# PRINCIPLES FOR

# Children's Coverage in Health Care Reform

# NATIONAL ASSOCIATION OF CHILDREN'S HOSPITALS



Photo by David Watson, Children's Hospital of Wisconsin, Milwaukee, WI

ver the past few years, the National Association of Children's Hospitals has held a series of discussions about the future of children's health coverage with the leadership of children's hospitals, as well as a number of health policy experts and advocates. As a result of these discussions, N.A.C.H. adopted a set of principles for children's coverage.

In preparation for a health care reform debate,

these principles clearly articulate the elements necessary to make health care reform work for children. Facts and stories support these principles and demonstrate the need for a new look at the current state of children's health coverage and how our country can provide the best possible health care for all children.



## 1. All children should have health coverage, from birth through age 21.

Covering all children through a mix of publicly subsidized and private health insurance is an attainable first step toward covering all Americans and a cornerstone for lifelong health.

If all the children eligible for Medicaid and CHIP were enrolled today, the number of uninsured children would drop by 70 percent from 8.8 million to less than 3 million.

- 60 percent of children have private health-insurance coverage, and 28 percent have public coverage through Medicaid and CHIP. 11 percent are uninsured.
- 70 percent of uninsured children come from families with incomes at or below two times the federal poverty level.

Having health coverage makes a lifelong difference for children's health and provides long-term benefits for society.

- Uninsured children are eight times more likely to have delayed care and 12 times more likely to have an unmet medical need than children with private insurance.
- Many adult chronic health conditions have their origins in childhood.

## 2. Children's coverage should be comprehensive and reflect their health and development needs.

Children's health insurance should cover medically necessary care and reflect the unique health care needs of children.

Most children (70 percent) are generally healthy and only require age appropriate immunizations, prevention and primary care, and treatment for acute illness or injury.

 Children's health care is relatively inexpensive on average – less than half that for non-elderly adults.

Approximately 13 - 15 percent of children have chronic conditions that require more health services and care coordination, and the prevalence of those conditions has risen dramatically.

- The prevalence of asthma, the number one cause of emergency room visits for children, increased from 4 percent to 9 percent from 1980 to 2005.
- The prevalence of obesity among children has sharply increased from 6 percent of all children in 1980 to 18 percent by 2004.

"Doctors are seeing ... boys and girls in elementary school suffering from high blood pressure, high cholesterol and painful joint conditions; a soaring incidence of Type II diabetes; even a spike in child gallstones, also once a singularly adult affliction. Minority youths are even more severely affected..."

- The Washington Post May 17, 2008, "Obesity Threatens a Generation," Susan Levine and Rob Stein  $\,$ 

# Children's illnesses, diseases and conditions often differ from adults; and prevention, treatment and coverage guidelines for adults can be inappropriate for children.

- Rehabilitation guidelines for adults, which require improvement or restoration of function, can be inappropriate for a toddler or a child with cerebral palsy.
- Differences in the biology of tumors in children and adults usually make it difficult to prescribe drugs for children based on adult data.

"A child is not just a little adult. They are still developing and changing. Their systems are still in the process of maturing and being fine tuned."

 Daniel Ludwig, M.D., Children's Hospital Boston, The Washington Post May 17, 2008, "Obesity Threatens a Generation"

# 3. Affordable coverage should be available to all children, no matter where they live.

Federal policies should move toward uniform eligibility levels for guaranteed publicly subsidized coverage. Federal standards should ensure simple eligibility determinations based on income, not assets, as well as streamlined enrollment.

# Access to affordable health care coverage varies significantly among states.

- A child's chances of being uninsured vary dramatically among states, from a low of
  one in 30 children in Massachusetts to a high of one in five children in Texas. State variations
  in coverage exist for many reasons, including the availability of employer-sponsored insurance
  and varying eligibility rules and barriers to enrollment in public coverage.
- The percentage of uninsured children has increased in 32 states since 2004. It decreased in only 18 states and the District of Columbia.

#### For many families, the cost of health care is substantial.

- Children are disproportionately poor. One in five lives in families with incomes below poverty; two in five live in families below 200 percent of poverty.
- Sixteen percent of families with public coverage had out-of-pocket health costs that exceeded 10 percent of the family income.
- In 2007, the average cost of employer-based family coverage was \$12,106. Without employer subsidy, that cost would consume 35 percent of a family of four's income at 200 percent of poverty and 20 percent at 300 percent of poverty.



Photo by Allen S. Kramer, Texas Children's Hospital, Houston, TX

## 4. Children's coverage should provide access to appropriate care.

Coverage should provide all children with a medical home and the right care at the right time. Public subsidies should be sufficient to prevent discrimination between publicly and privately insured children.

Uninsured children and lower income children are more likely to lack a usual source of care – and more likely to forego or delay care and be admitted to hospitals through emergency rooms.

- 32 percent of uninsured children had no usual source of care compared to four percent with public coverage and two percent with private insurance.
- Children with family incomes below 200 percent of poverty were three times more likely to have no usual source of care than those above 200 percent of poverty.

A medical home – an ongoing source of comprehensive health care – has been identified as a priority for child health reform at national and state levels, but that goal is far from met, and public coverage payments are far from sufficient.

- In 2003, more than half of U.S. children (61 percent with public coverage and 47 percent with private insurance) did not have medical homes.
- Medicaid reimburses pediatricians, on average, at only 69 percent of the rate that would be paid under Medicare and 56 percent of commercial insurance rates.

Practicing pediatrician, Marsha Raulerson, M.D., testifying before the House Energy and Commerce Committee noted that her practice in Alabama is 70 percent Medicaid. In 2007, the practice did not break even because her Medicaid patients require so many services and payments are so low. Raulerson dipped into her own savings to keep her practice going. "Nevertheless, I believe that I have a calling to provide these services to this population, many of whom are children who have severe and long lasting health needs," Raulerson explained in her testimony.

### 5. Children's coverage should be continuous.

Public and private coverage should work collaboratively to ensure that children always have coverage. Families should be able to use public subsidies for premium assistance for employer-sponsored insurance for their children. Uniform eligibility policies and forms for public coverage should assure that children do not lose coverage if their families move across state lines.

More than twice as many children have gaps in coverage during the course of a year as those uninsured for the whole year.

- Four million children under 18 were uninsured for the entire year in 2005. Nearly 9 million children experienced interrupted and discontinuous coverage during the same year.
- Children with discontinuous coverage are 50 percent more likely than others to lack a regular source of care, which results in a tenfold increased risk of hospitalizations for preventable conditions.

For low income children eligible for Medicaid or CHIP, renewal and retention are a serious challenge in improving children's health coverage.

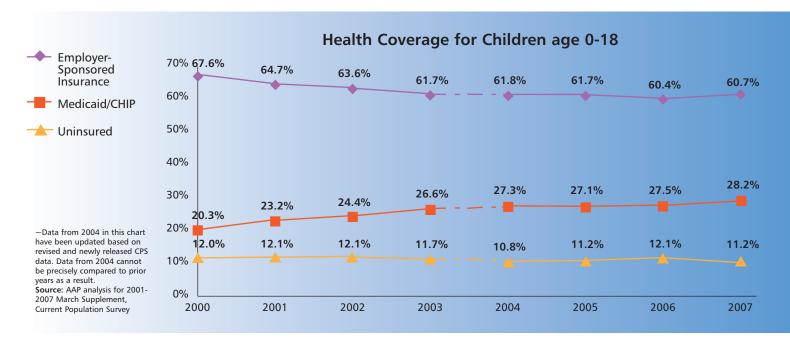
- Both Medicaid and CHIP have far too many eligible children losing coverage (12 – 16 percent) each year.
- Separately run and administered CHIP and Medicaid programs expand the cracks through which children can fall, increasing their risk of dropping out of coverage by 45 percent.

# 6. A national commitment to employer-sponsored insurance and a health care market place with multiple payers should be maintained.

Reform should maximize choice of coverage and providers and minimize "crowd-out" of privately financed coverage. Guaranteed coverage for all children should include a commitment to employer-sponsored insurance, as well as a market place of multiple payers. Health plans and providers should compete on the quality and delivery of the services they provide.

Although employer-sponsored insurance is eroding, the majority of children (55 percent) continue to have health insurance through their parents employers. From 2000 – 2004, employer-sponsored insurance coverage declined by 5.3 percent for children and 4.8 percent for adults.

- While Medicaid and CHIP have picked up much of the loss of private coverage for children, the ability of these programs to pick up all of it has varied. Between 2004-2006 the number of uninsured children rose but in 2007 the number of uninsured children decreased due to state coverage expansions and the easing of enrollment barriers.
- The number of employers offering health insurance has decreased from 69 percent in 2000 to 60 percent in 2007. The declining percentage of small firms (3-199 workers) is the driving factor in the overall decrease. Small firms' offer rate has fallen from 57 percent in 2000 to 45 percent in 2007 whereas large firms have remained steady at 99 percent.
- Only a small percent (6 percent) of children had families who dropped private coverage to gain public insurance, according to a 2002 study of CHIP enrollees. Almost half of the families lost or changed jobs.



Private coverage is becoming less affordable for families, particularly lower income working families.

• Annual increases in out-of-pocket health expenses and premiums averaged 8.3 percent during 2001 – 2004, while average family incomes increased only 1.6 percent.

Public subsidies for children's coverage should assist families choosing creditable employersponsored insurance family coverage as well as public programs.

• An increasing number of families have a mix of public and private insurance – 11.3 percent of single parents/children in 1997 compared to 19.1 percent in 2005.

# 7. System reform should be an integral part of health care reform.

Ensuring access to both affordable coverage and affordable care will require system reform for a high performance, high quality health care system that can integrate health care services and align incentives to improve outcomes and control costs.

Although U.S. children's physical health in many respects is the best it has ever been, health disparities and shifts in children's illnesses from acute to chronic disease are poorly addressed by the current health system.

- Disparities based on socioeconomic status persist; and the magnitude of disparities seems to increase as children age, indicating that the health system is not responding as well as it should.
- Coverage and reimbursement patterns continue to generate major disincentives to the development of medical homes and comprehensive approaches to the management of children with chronic conditions.
- These shortcomings can be even more detrimental to children than other age groups, given their growth and development and the potential impact of early investments for their health and well-being.

The reduction in acute illness in children has dramatically elevated the relative importance of treating chronic diseases and developmental conditions for children.

 Outpatient care for children grew rapidly from 1962 to 2000, while hospitalizations declined 45 percent. At the same time, hospital care shifted toward children with chronic disease and greater severity of illness. Hospital days for children with two or more admissions grew from 4 to 25 percent.

These trends underscore the importance of preventive and primary care and greatly increase the impact of organized, regionalized pediatric specialty care systems.

- Regionalization of care is particularly important to children, since it ensures the patient volume and resources essential to state-of-the-art expertise and high-quality specialized care. For example, 89 percent of pediatric care for cancer and cystic fibrosis in the United States is provided by children's hospitals (3 percent of all hospitals).
- A critical shortage exists in many pediatric subspecialties, locally and nationally. For example, in 2003, seven of 16 pediatric subspecialties were present in less than one half of hospital referral regions.
- Yet, Medicaid, in particular, often does not adequately pay for physician services or regionalized tertiary or trauma care across state lines.

In order to get the specialized care needed for his heart condition, Brendan travelled to three different hospitals in three different states. Just hours after his birth in March 1999, Brendan was airlifted to a children's hospital from Virginia to Philadelphia to reach a team of cardiologists ready to perform open heart surgery. Several years later, he received a heart transplant at another children's hospital in Maryland. Throughout these years, Brendan received ongoing care at the children's hospital closest to his home in Northern Virginia.

# 8. The federal government must play a leading role in health care reform for children.

Health coverage for all children and system reforms to improve the delivery, quality and integration of their health care cannot be achieved on a state-by-state basis. Stronger federal standards and improvements in Medicaid and CHIP will be required.

Medicaid and CHIP are the largest insurers of children in the United States, covering one of three children. If all eligible children were enrolled, the proportion would increase to two in five children.



Photo by Cynthia Brodoway, Alfred I. duPont Hospital for Children, Wilmington, DE

Most quality measurement, reporting and performance improvement efforts have been focused on adult care with federal leadership through Medicare. There has been no equivalent federal leadership on the quality of children's health care.

• Medicaid and CHIP currently ask states to voluntarily report on only four measures related to children.

When it comes to getting the right care at the right time, insured children in this country fare even worse than adults, according to a study released in October 2007 examining the quality of health care for American's children.

- The study conducted by the Rand Corporation, Seattle Children's Hospital Research Institute and the University of Washington's School of Medicine found that children received only 68 percent of recommended care for acute medical problems, 53 percent of recommended care of chronic medical conditions, and 41 percent of recommended preventive care.
- Children with asthma received just 46 percent of the care they needed.

"Getting children covered simply isn't enough. Additional steps are required to ensure that necessary care is delivered. That will require greater investment in health information technology systems as well as increased attention to documenting and measuring quality of care for children."

-Elizabeth A. McGlynn, Ph.D., senior study author and associate director of RAND Health.

About two-thirds of drugs prescribed for children have not been studied and labeled for pediatric use, thus placing children at risk of being exposed to ineffective treatment or incorrect dosing, according to the U.S. General Accounting Office.

• Pediatric studies, most involving older drugs, found that 87 percent required labeling changes, often because they were being prescribed to children improperly.

# 9. Even with successful health care reform, Medicaid has an indispensable role in meeting the long-term and community-based care needs of children.

Medicaid has a unique role in meeting the many long-term and personal care needs of children with special health care needs as well as for the frail elderly and persons with disabilities. This role cannot be fully met by health care coverage.



Photo by Alan Fethiere, Shriners Hospitals for Children - Chicago, Chicago, IL

The role of Medicaid coverage has historically extended beyond commercial health insurance, filling certain gaps in both Medicare and private health insurance, particularly for the broad array of services that people with severe disabling conditions might need.

• Twenty-nine percent of children with special health care needs are covered by public insurance, and another 8 percent are covered by both private and public insurance.

Medicaid's coverage standard for children has major implications for the quality of pediatric care, particularly for children with special health care needs. It requires coverage of all items and services falling within the federal definition of "medical assistance" that are medically necessary to correct or ameliorate physical and mental conditions and illnesses.

Peter, born with a craniofacial birth defect called Goldenhar Syndrome, has had many surgeries to repair a cleft palate, reconstruct his lower jaw, and remove a bronchial cyst and a cyst on the eye. In addition to these surgeries, he had a tube placed in his trachea to help him breathe for the first four years of his life, and, in a couple of years, he will have to undergo major surgery to reconstruct his trachea and close the hole in his neck.

Peter has private insurance but also relies on Medicaid to provide services not covered by his primary insurer. Because of Medicaid, Peter was able to receive private duty nursing at night to monitor the many devices he was hooked up to, including oxygen, a feeding tube and pump, and a device to measure the percent of oxygen in his blood. Without Medicaid, Peter would not continue receiving occupational therapy, which is helping him make the transition from a feeding tube to solid food. Medicaid also provides prescription coverage and durable medical equipment supplies that are not covered by his private insurance. Peter just finished first grade and loves to read, play video games and cheer on the Detroit Red Wings.



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