



National Initiative for  
Children's Healthcare Quality

*A Better Return on Investment: Improve Children's Healthcare—A Policy Brief  
from the National Initiative for Children's Healthcare Quality*



**PREPARED BY:**

**Charles J. Homer MD, MPH, President & CEO, NICHQ**

**Lisa A. Simpson MB, BCh, MPH, FAAP, Director of the Child Policy Research Center, Cincinnati Children's Hospital Medical Center**

**Debbie Chang MPH, Vice President of Policy and Prevention, Nemours**

*The authors wish to thank NICHQ's Policy Committee for its thoughtful input and review. The members of the committee are Stephen Berman , Christina Bethel , Charles Bruner, Alexandra Charrow, Debbie Chang, Anne DeBiasi, Aaron D'Elia, Maia Fedyszyn, Neal Halfon, Bob Hall, Allan Kornberg, Anne Langley, Brooke Lehmann, Erika McCarthy, Rachelle Mirkin, Lee Partridge, James Perrin, Ed Schor, Judith Shaw, Lisa Simpson, Jessica Taubner, and Marina Weiss. We particularly want to acknowledge helpful comments from Polly Arango, member of NICHQ's Board of Directors. The opinions represented in the brief are those of the authors.*

## Introduction

Comprehensive health reform is a priority of the nation. Health reform in 2009 seeks to:

- assure affordable, quality health coverage for all Americans,
- reduce long-term growth of healthcare costs,
- promote “prevention and wellness,” and
- improve patient safety and quality of care.<sup>1</sup>

A renewed health system can only achieve these goals if it performs better than the current one does for America’s children. Improving the children’s healthcare system is essential because:

- American children experience worse health and higher levels of mortality than do children from most other developed nations<sup>2</sup>, and
- The future health of the adult population and the trajectory of America’s healthcare costs depend on the good health and health behaviors established in childhood.

Improving the performance of the healthcare system for children will require a broad set of reforms addressing:

1. The providing of universal coverage and benefits appropriate to child needs, including assuring that children now covered through Medicaid and CHIP retain the proven benefits of Medicaid’s EPSDDT;
2. An expert and appropriate work force;
3. Health information technology specific to the developmental and epidemiologic needs of children;
4. Better mechanisms of payment that are both less burdensome and more aligned with addressing child health needs;
5. Enhanced community preventive services; and
6. An approach to performance measurement and quality improvement that is both effective and specific to children’s healthcare.

This report will focus only on the last of these elements, touching on the others only as they relate to improving quality, as other organizations will focus on reforms 1-5.

Children’s health is distinct from adult health in three ways:

- A. Because children are developing, depend on their families, and are strongly influenced by the health of their communities, the children’s healthcare system has broader end goals than does the adult system

---

<sup>1</sup> Principles for Health Reform [www.whitehouse.gov](http://www.whitehouse.gov) (visited May 10, 2009)

<sup>2</sup> UNICEF. The State of the World’s Children. 2009. <http://www.unicef.org/sowc09/index.php>. (visited April 10, 2009)

- B. Because children’s health needs—the epidemiology of children’s health-- are different than those of adults, distinct emphases on healthcare quality improvement are needed
- C. Because the organization and financing of services for children are distinct from that of adults, a customized approach to the structure and design of quality measurement and improvement activities is necessary.

**A. Goals.** Because children are developing, depend on optimal families, are strongly influenced by the health of their communities, and are the poorest and most diverse segment of our population, a high performing children’s healthcare system enables:

- Children to achieve their greatest potential, promoting optimal health and development, while causing no harm—delay, injury, pain, suffering, or death
- Families to better provide for, promote, and support their child’s health and well being
- Communities to effectively support the health of their children and families and
- Society to achieve these results with equality and without waste.

**B. Needs:**

Most children are healthy. Their key health need is to stay healthy, develop health promoting behaviors and avoid health risks that can lead to long term harm. Some children—roughly 15%--have one or more chronic conditions or disabilities (special healthcare needs)—with even a higher proportion if children with obesity are included. A few of these special healthcare needs, such as asthma, are common. Most, such as cerebral palsy or autism, are relatively rare<sup>3</sup>.

Children are the most economically disadvantaged and culturally diverse segment of our society. Poverty and minority status continue to be strongly associated with disparities in care and poorer health.<sup>4</sup> These health disparities lead to long term disadvantage both in health, and in educational and economic achievement.<sup>5</sup>

Based on these needs, a key priority for pediatric quality improvement is to assure not only that every child has access to a family centered, primary care medical home, but that these medical homes function at a high level. For the majority of children, this means being able to deliver evidence based or informed preventive care more reliably. Such care should address physical health risks, such as obesity; promote healthy

---

<sup>3</sup> Perrin JM, Bloom SR, and Gortmaker SL. The Increase of Childhood Chronic Conditions in the United States. JAMA. 2007;297(24):2755-2759

<sup>4</sup>Wise PH The Transformation of Child Health in the United States. Health Aff (Millwood). 2004 Sep-Oct;23(5):9-25

<sup>5</sup> Wertheimer R CT, Moore K, Hair E. Attending Kindergarten and Already Behind: A Statistical Portrait of Vulnerable Young Children Washington, DC: Child Trends December 2003.

emotional development; and establish linkages to effective community based preventive services.

Improvement activities should also prioritize strengthening the capability of the primary care medical home to manage more comprehensively and effectively the care of children with the most common special healthcare needs, as well as facilitate access to appropriate specialty expertise. Optimal care for children with the less common special healthcare needs requires co-management between primary and specialty care, in turn requiring effective care coordination and information exchange facilitated through health information technology. National activities are required to amass sufficient data to identify and share best practices for care of children with these less common conditions and needs, as well as identify and address disparities.

A child oriented system to monitor and improve system performance should prioritize measures of disparities and the strategies to address them.

### C. Organization and finance:

Most healthcare for children is delivered in small primary care settings. Hospitalization is rare. When hospitalized, up to 70 percent of children are treated in community hospitals. Children with complex special healthcare needs most often receive inpatient care in specialized hospitals that typically consume the greatest share of children's healthcare resources.<sup>6</sup> Medicaid and CHIP—state operated programs-- are the largest funders of children's healthcare.<sup>7</sup> Families provide the patient voice in children's healthcare, particularly for younger patients

Because of these system characteristics, mechanisms are required to measure and support quality improvement in primary care settings, community hospitals and in children's specialty hospitals. This will require activities and programs at the community, state and federal levels. Families should be centrally involved in directing improvement priorities. Payment mechanisms will need change to promote alignment with the broad system goals articulated above.

**Coverage and Continuity:** These policies and programs rest on the assumption that all children will have health insurance coverage, and that this coverage includes benefits specific to the needs of children (such as those contained in the Early, Periodic, Screening, Diagnosis and

---

<sup>6</sup> Owens PL, Zodet MW, Berdahl T, Dougherty D, McCormick MC, Simpson LA. Annual Report on Healthcare for Children and Youth in the United States: Focus on Injury-related Emergency Department Utilization and Expenditures. *Ambul Pediatr.* 2008 Jul-Aug;8(4):219-240.e17. Epub 2008 May 27

<sup>7</sup> Newacheck PW, Kim SE. A National Profile of Healthcare Utilization and Expenditures for Children with Special Health Care Needs. *Arch Pediatr Adolesc Med.* 2005 Jan;159(1):10-7

Treatment, EPSDT, benefit under Medicaid). Public and private insurance programs should have measures and programs that assess their performance in enrolling and maintaining continuous coverage for children as well as performance in quality of care. *The approaches advocated for in this brief should be applied to the system of care for children and families regardless of the source of their coverage*

## **Policy Recommendations**

**We recommend the following specific policies to enhance quality of care for children in the context of health reform:**

- 1. Assure that the specific needs of children in each quality related element of health system reform are addressed. These elements include, but are not limited to, the overall quality and cost strategy, measurement, improvement resources, medical home, health information technology, and comparative effectiveness research.**
- 2. Create a system of national and regional/state children’s quality improvement resources that improve care and support the family centered medical home.**
- 3. Institutionalize the family voice in healthcare improvement**
- 4. Design health information systems to address the specific health needs of children.**
- 5. Create more comprehensive measures and assessment tools**

- 1. Assure that the specific needs of children in each quality related element of health system reform are addressed. These elements include, but are not limited to, the overall quality and cost strategy, measurement, improvement resources, medical home, health information technology, and comparative effectiveness research.**

Quality improvement initiatives designed and implemented to address adult healthcare needs will not effectively address the health needs of children. The overwhelming short term costs of adult care and the direct involvement of the Federal government in that care through Medicare will crowd out any Federal focus on children unless there is a clear mandate through legislation for quality improvement in children’s healthcare and programs are held accountable for child specific performance.

- 2. Create a system of national and regional/state resources that promote quality care for children and support the family centered medical home.**

Establish a national resource center and state level “extension” programs to promote transformed quality of care for children. Such programs can be separate from programs for adult healthcare or can be incorporated within a single program; if the latter, specific elements must be defined for child health and programs held accountable specifically for children’s healthcare results.

## Federal Infrastructure

- **Establish a national resource center with a specific charge to address children’s health care:** The Center will:
  - **Inform national priorities for improving children’s healthcare:** The center will inform national priorities for improvement in child health, based on assembling a broad range of stakeholder perspectives and analyses of quality performance data specific to children. Typical consensus groups may not sufficiently emphasize or understand the child health perspective.
  - **Develop pediatric quality improvement tools:** The center will identify or develop and test quality improvement tools and materials to facilitate improvement within the delivery system that can be applied by regional and state extension programs (below).
  - **Conduct and support quality improvement learning collaboratives:** — Learning collaboratives improve quality through the use of data and participation of clinical staff, health professionals, consumers, and families.<sup>8</sup> The Center will conduct improvement collaboratives on a national scale is appropriate for driving change for those issues affecting specialty pediatric hospital care and care for children with less common special healthcare needs, and support the capacity of state programs to conduct collaboratives for primary care practices and community hospitals..
  - **Facilitate the creation of national electronic registries** to identify best practices for care of children with less common special healthcare needs that will form the basis for improvement. .
  - **Expand the pediatric quality improvement workforce:** by creating a Children’s Quality Improvement Corps (CQuIC), modeled on the CDC’s Epidemiology Intelligence Service. This program will train health professionals in the methods of quality improvement and assign them to states and organizations that deliver care to children, and provide needed capacity.
  - **Provide a forum for sharing best practices in state based child health improvement:** State programs will benefit from a Forum for exchange of best

---

<sup>8</sup> The Commonwealth Fund Commission on a High Performance Health System, The Path to a High Performance U.S. Health System: A 2020 Vision and the Policies to Pave the Way, The Commonwealth Fund, February 2009

practices in design and execution of measurement and improvement activities and policies.

- Promote innovation: The Center will create mechanisms, including web technologies and meetings, to identify and promote development and spread of innovative practices in children's healthcare.

### State/Regional Infrastructure

- Establish state and regional extension programs to promote improvement and transformation. Such programs will help practices, hospitals, and other providers improve the quality of children's healthcare services, as well as coordinate healthcare services with other community resources.<sup>9</sup> The state-level centers will:
  - **Provide or make available services to support family centered medical homes:** These services will include developmental and mental health screening, care coordination, and health resource navigation not feasible for typical primary care practices to provide on their own.
  - **Provide quality improvement assistance to support practice transformation to become family centered medical homes:** This assistance will provide coaching to practices on how to undertake change, engage with families, enhance access, better perform chronic care management and preventive services and use health information technology to improve care.
  - **Conduct improvement projects:** These programs will conduct projects that focus on health issues specific to the needs of the region and state. These will address both hospital care (especially at the community hospital level), ambulatory and primary care, and community health issues (such as obesity) that span community and clinical services.
  - **Establish productive partnerships** with key organizations involved in the delivery and oversight of services for children, include professional associations, state and city public health programs, insurers, consumer groups and Family to Family Health Information Centers, hospitals and hospital associations, and others as needed.
  - **Address oral and mental health needs:** These programs will support the provision of high quality oral and mental health services, both through

---

<sup>9</sup> Community Care of North Carolina Website <http://www.communitycarenc.com/> (Visited May 7, 2009)



integration with primary care and through improving care in specialty settings.

- **Inform Medicaid, CHIP and Health Insurance Exchange** on the needs of medical homes and design of appropriate payment systems to encourage care consistent with the family centered medical home model.

### **3. Institutionalize the family voice in healthcare improvement**

Families and consumers provide the critical perspective in a transformed health system. Training and support can enhance parents' effectiveness in improving children's healthcare. Family-to-Family Health Information Centers (F2Fs), now operating in every state throughout the country with modest funding, were conceived by family leaders and their professional partners as cost-effective and efficient mechanisms for providing objective information to families and providers who must navigate increasingly complex health and related systems for children. We recommend strengthening the capabilities of Family-to-Family Health Information Centers by providing resources so they can more effectively train parents, other caregivers, and youth to participate in quality improvement initiatives, working with the state quality improvement programs described above.

### **4. Design health information systems to address specific child health needs**

Additional policies are needed to assure that health IT benefits child health. IT policies must consider issues beyond the funding already provided by CHIPRA and ARRA for the development of a pediatric electronic health record and adoption of EHRs respectively. Health reform legislation should provide for the development of:

- **Community and State level practice registries:** Pooling of patient information into registries and data bases will not only benefit individual patient by coordinating and integrating care—they will also prove imperative as public health tools to link the health relevant data of different systems that care for children. Registries will aid in the monitoring of care in medical homes, in public health tracking, and in assuring longitudinal progress from infancy to young adulthood. These registry systems should include immunization, BMI (body mass index, a measure of obesity) as well as link with state newborn screening registries for hearing, genetic disorders, lead poisoning and other public health matters.
- **Rare condition national registries:** While there are numerous childhood chronic diseases, many are rare. Registries assimilated at the federal level will allow for the tracking and assessment of care for the rarest of illnesses allowing for the development of best practices even when sample sizes are limited.

- Facilitate production of performance measures, including those required through CHIPRA and now in wide use through HEDIS measurement.

## 5. Create more comprehensive measures and assessment tools

The Child Health Insurance Reauthorization Act (CHIPRA)<sup>10</sup>, reauthorized in February of 2009, provides funds and a process for the development and use of pediatric quality measures by state SCHIP and Medicaid programs. In addition to the excellent start that CHIPRA provides, we recommend:

- **Measures be expanded to be applied to populations outside Medicaid and CHIP.**
- **Measures address the quality of behavioral and emotional pediatric healthcare.** As the prevalence of depression, ADHD, and other mental health issues continues to grow in the pediatric population, measure to assure effective prevention, diagnosis, assessment, and treatment of mental health disorders are more crucial than ever.
- Measures assess the quality of the family centered medical home as it applies to pediatric health.
- Measures reflect the coordination of care, including between healthcare and non-healthcare systems (schools, early intervention) and transition between pediatric and adult care.

---

<sup>10</sup> United States. Cong. Senate. 111<sup>th</sup> Congress, 1<sup>st</sup> Session. S. AMDT.46 : The Child Health Insurance Reauthorization Act [Introduced on the floor of the Senate, January 21st , 2009]