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.1

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 nations2, 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.

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.

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 resources that promote quality care for children and support the family centered medical home:**
   - **Federal Infrastructure:** Establish a national resource center with a specific charge to address children’s health care.
   - The purpose of this Center will include:
     - Setting national priorities for improving children’s healthcare
     - Developing pediatric quality improvement tools
     - Conducting quality improvement learning collaboratives
     - Facilitating the creation of national electronic registries
     - Expanding the pediatric quality improvement workforce
     - Providing a forum for sharing best practices

   - **State/Regional Infrastructure:**

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1 Principles for Health Reform [www.whitehouse.gov](http://www.whitehouse.gov) (visited May 10, 2009)
Establish state and regional extension programs to promote improvement and transformation. More specifically, the state-level centers will:

- Provide or make available services to support family centered medical homes
- Provide quality improvement assistance to support practice transformation
- Establish productive partnerships with organizations involved in the delivery of services for children, such as professional associations, state and city public health programs, consumer groups and family to family health information centers, hospitals, etc.
- Address oral and mental health needs

3. **Strengthen the family voice in healthcare improvement**

Families and consumers provide the critical perspective in a transformed health system. We recommend strengthening the capabilities of Family-to-Family Health Information Centers in the arena of training parents, other caregivers, and youth to participate in quality improvement initiatives.

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

Additional policies are needed to make health IT benefit child health beyond the funding already provided by CHIPRA and ARRA for the development of a pediatric electronic health record and adoption of EHRs respectively. Specifically, health reform legislation should provide for the development of:

- **Community and State level practice registries**: Registries will aid in the monitoring of practice care and in public health tracking of immunization, BMI, newborn screening, etc.
- **Rare condition national registries**: 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)³, 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 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-health care systems (schools, early intervention) and transition between pediatric and adult care.
- Composite measures that better reflect the full complement of services that children need for either prevention or care of chronic illnesses.

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