

**The President's New Freedom Initiative:
Fulfilling America's Promise to Americans with Disabilities
&
The Six Core Measures for Children with Special Health Care Needs**

The President's New Freedom Initiative: Fulfilling America's Promise to Americans with Disabilities charges the U.S. Department of Health and Human Services Health Resource Services Administration (HRSA) with developing and implementing a plan to achieve appropriate community-based systems for children and youth with special health care needs and their families (as specified in "Delivering on the Promise" under Solution III. C, New Freedom Initiative). This plan will provide Six Core Measures for Children and Youth with Special Health Care Needs:

- 1. Family Participation and Satisfaction**
- 2. Access to Medical Home**
- 3. Access to Affordable Insurance**
- 4. Early and Continuous Screening**
- 5. Easy-to Access Community-based Service Systems**
- 6. Services Necessary to Transition to Adulthood**

<http://mchb.hrsa.gov/cshcn05/MCO/intro.htm>

**The President's New Freedom Initiative:
Fulfilling America's Promise to Americans with Disabilities
"Delivering on the Promise"**

**U.S. Department of Health and Human Services
Health Resource Services Administration (HRSA)**

SOLUTION III.C

**ACTION PLAN FOR CHILDREN AND YOUTH WITH SPECIAL HEALTH CARE
NEEDS AND THEIR FAMILIES**

HRSA's Maternal and Child Health Bureau will take the lead in developing and implementing a plan to achieve appropriate community-based services systems for children and youth with special health care needs and their families. Components of the plan may include:

- 1. Development of community-based systems of services that are inclusive of children with special health care needs (CSHCN) and their families, where substantial decision-making authority is devolved from the federal government to the states to the communities.**
- 2. Recognition that families are the ultimate decision-makers for their children and encouragement of participation in making informed decisions.**
- 3. Development of standardized elements of the medical home for CSHCNs. In addition, the agency will develop and disseminate models of the medical home, and provide additional training resources to primary care professionals to develop medical homes.**
- 4. Review of the variety of reimbursement mechanisms that impact children with special health care needs.**
- 5. Through the Maternal and Child Health Block grant (Title V of the Social Security Act), and the Newborn Genetics Program (Title XXVI of the Child Health Act), expansion and strengthening of newborn screening systems and promote ongoing screening of CSHCN (incorporating EPSDT into the medical home concept).**
- 6. Ensuring that youth with special health care needs receive the services necessary to transition to all aspects of adulthood, including from pediatric to adult health care, from school to employment and to independence.**

BARRIER ADDRESSED BY SOLUTION

For children with special health care needs, specific barriers include access to:

(1) comprehensive, family-centered care; (2) affordable insurance; (3) early and continuous screening for special health care needs, and (4) transition services to adulthood. With respect to families of such children, issues relate to family satisfaction and the complexity and organization of services resulting from fragmentation and multiple funding streams. Developing a plan to address these barriers is a necessary first step to improving access to community-based services for children with special health care needs.