



## REQUEST FOR PUBLIC COMMENT

### Maternal and Child Health Bureau Family Health Systems

#### 2013 Title V Maternal and Child Health Block Grant *Children with Special Health Care Needs Supplement*

***NOTE: This request for public comment specifically addresses children with special health care needs and is supplemental to a general request for public comment for the entire 2013 Title V MCH Block Grant Block Grant Application.***

#### **I. Summary of Data on Children with Special Health Care Needs (CSHCN):**

Based on rates from the 2009-2010 National Survey of Children with Special Health Care Needs (NSCSHCN) of families of children to age 18, approximately 36,100 Delaware children (17.5%) younger than age 18 years may have a special health care need.

The NSCSHCN Survey data suggest that in 2009-2010 about 19.3% of Delaware's CSHCN younger than age 18 years had one or more unmet needs for specific health care services. Rates were higher for Black (24%) and Hispanic children (27.2%). In regards to income status, 27.5% of children with special health care needs living in families less than 100% Federal Poverty Level (FPL) had unmet needs.

The survey data also indicate that 35.8% of all Delaware CSHCN are without family-centered care. More than 50% of Hispanic (51.4%) and 48.1% of Black CSHCN are without family-centered care, in comparison to 27.9% for Caucasian.

Based on findings from the 2007 National Survey of Children's Health (NSCH), a number of key disparities have been identified for CSHCN when compared to their peers without special needs. These disparities are evident across four key areas: physical health (overall health and oral health); emotional and mental health; health care access and quality; and family health.

The data on unmet needs, lack of family-centered care, lack of a medical home, and health disparities identified for CSHCN compared to those without special needs clearly indicate that the Bureau invest time and resources in collaborative partnerships, coordinated care, reach out to families for input and identify opportunities for family involvement in program planning, implementation and measuring success.

## II. Overview of Federal Priorities for CSHCN:

The Title V Maternal and Child Health Block Grant requires all states and territories to report on a core set of 18 Performance Measures each year. Among these 18 performance measures are five specifically related to CSHCN. These are:

- **Federal PERFORMANCE MEASURE #2:** *The percent of children with special health care needs age 0-18 years whose families partner in decision making at all levels and are satisfied with the service they receive.*
- **Federal PERFORMANCE MEASURE #3:** *The percent of children with special health care needs age 0-18 who receive coordinated, ongoing, comprehensive care within a medical home.*
- **Federal PERFORMANCE MEASURE#4:** *The percent of children with special health care needs age 0-18 whose families have adequate private and/or public insurance to pay for the services they need.*
- **Federal PERFORMANCE MEASURE #5:** *Percent of children with special health care needs age 0 – 18 whose families report the community-based service systems are organized so they can use them easily.*
- **Federal PERFORMANCE MEASURE #6:** *The percentage of youth with special health needs who received the services necessary to make transitions to all aspects of adult life, including adult health care, work, and independence.*

## III. Overview of State Priorities for CSHCN:

In addition to the federal priorities and performance measures states are required to determine a core set of state priorities and performance measures specific to their needs. The state performance measures related to children with special health care needs are to establish a network for organizations serving CSHCN and their families and to decrease health disparities between CSHCN and children without any special health care needs. The performance measures to track progress on these priorities are:

- **State PERFOMANCE MEASURE:** *The percent of benchmark measures completed for implementation of a formal umbrella structure for organizations serving families with children with special health care needs in Delaware.*
- **State PERFORMANCE MEASURE:** *The percent of health indicators that improve (child health, emotional and mental health, health care access and quality, and family health) for families and children with special health care needs in Delaware compared to health indicators among children without special health care needs.*

#### **IV. Delaware’s Family Support and Healthcare Alliance Delaware (Family SHADE).**

The Title V Maternal and Child Health Block Grant Program requires states to set aside at least 30% of its federal funds for Children with Special Health Care Needs. In Delaware, a large portion of this set aside funding is allocated to Family SHADE.

Family SHADE is an alliance of 40+ organizations and agencies committed to working together to improve the quality of life of children with special health care needs by improving access to information and services in Delaware. Family SHADE was formed in response to a needs assessment of families and service providers conducted by Delaware’s Maternal Child Health Bureau. The results of the needs assessment indicated the need to strengthen, expand, and coordinate a system of family supports that are easily accessible, avoid duplication, use resources efficiently, and prevent gaps in services to families of CSHCN throughout Delaware. To address these recommendations, organizations, agencies and family members came together to form Family SHADE, an “umbrella” organization that is specifically dedicated to sharing information, resources and expertise to benefit and support families of CSHCN.

#### **V. Make sure your voice is heard:**

Please consider the following, as well as any additional comments or questions you may have, and provide your feedback to Bhavana Viswanathan, [bhavana.viswanathan@state.de.us](mailto:bhavana.viswanathan@state.de.us) by July 16, 2012.

If you have any questions, please contact Bhavana Viswanathan ([bhavana.viswanathan@state.de.us](mailto:bhavana.viswanathan@state.de.us)) or Walt Mateja ([walt.mateja@state.de.us](mailto:walt.mateja@state.de.us)), or you may reach either by phone at (302) 744-4551.

- If you could give advice to service providers about how they can improve family/individual involvement in decision-making, what would you say?
- Do you feel that our priorities are on in line with the needs of families with children with special health care needs?
- Is there anything else you would like to tell us that would help us understand how families of children with special health care needs can be served better in Delaware?

For an overview of Delaware’s Title V Maternal & Child Health Performance Measures and funding, as reported in the latest block grant application, see

<https://perf-data.hrsa.gov/MCHB/TVISReports/Snapshot/snapshot.aspx?statecode=DE>