

**TESTIMONY BEFORE THE BUDGET COMMITTEE ON HUMAN SERVICES
OCTOBER 4, 2005**

Chairman Dever, members of the committee, I am Tamara Gallup-Millner, Director of the Children's Special Health Services Unit for the Department of Human Services. I appear before you to provide information regarding the Children's Special Health Services program.

The primary funding source for Children's Special Health Services is the Maternal and Child Health Services Block Grant. The general purpose of this grant is the improvement of the health of all mothers and children consistent with the applicable 2010 health status goals and national health objectives. To receive grant funding, the State submits an application each year that requires a plan for meeting needs identified through a statewide needs assessment process.

For children with special health care needs, the grant is to be used for two primary purposes: 1) to provide and promote family-centered, community-based, coordinated care, including care coordination services; and 2) to facilitate the development of community-based, systems of services for such children and their families.

The Children's Special Health Services Unit supports the following programs to meet the purpose outlined above regarding direct care and services:

- Specialty Care Diagnostic and Treatment Services – payment for medical services for eligible children (medical and/or financial eligibility criteria applies to this program only)**
- Multidisciplinary Clinics – coordinated management of 10 different types of chronic health conditions**
- Care Coordination – county and public health staff help families access services and resources in the community, or when needed, across multiple service delivery settings**

- **Metabolic Food** – food and formula provision for individuals with phenylketonuria (PKU) and maple syrup urine disease (MSUD)
- **Russell Silver Syndrome** – payment for services related to growth hormone treatment and medical food
- **Information Resource Center** – public information services (e.g.) toll-free number, resource library, targeted outreach to disseminate health information, etc.

The second area of responsibility for the Children’s Special Health Services Unit includes activities to improve the health service system. Current efforts focus on building Maternal and Child Health capacity and are measured through the following national objectives for children with special health care needs:

- **Family Participation & Satisfaction** – Families of children with special health care needs will partner in decision-making at all levels and will be satisfied with the services they receive.
- **Access to Medical Home** – Children with special health care needs will receive coordinated, ongoing, comprehensive care within a medical home.
- **Early & Continuous Screening** – Children will be screened early and continuously for special health care needs.
- **Adequate Insurance** – Families of children with special health care needs will have adequate private and/or public insurance to pay for the services they need.
- **Community Based Systems of Care** – Community-based service systems will be organized so families can use them easily.
- **Transition to Adulthood** – Youth with special health care needs will receive the services necessary to make transitions to all aspects of adult life, including adult health care, work, and independence.

A report with the number of children served by Children’s Special Health Services is included with this testimony as attachment A – Children’s Special Health Services Program Data Report. The unduplicated number of children served in

FFY 2004 was 1,371. This number has been declining over the last few years, largely because the number of children seen in cardiac, cleft palate, and scoliosis clinics has decreased. Changes were expected in the scoliosis clinics because of screening changes at the local level and the consolidation of clinic sites that was planned with decreased referrals and our difficulty in recruiting orthopedists to staff the outreach clinics. The unduplicated number of 1,371 does not include individuals served through the Metabolic Food Program, the Russell Silver Syndrome Program or the Information Resource Center. Computer programming changes to the electronic client database used in Children's Special Health Services have now been completed, so in future, these individuals will be included.

Covered medical conditions are available in attachment B – Children's Special Health Services Medical Condition List. This list is used to guide eligibility for diagnostic and treatment services, the part of the program where we actually pay for medical care. The conditions on the list have evolved over time and were established with the advice of the Children's Special Health Services Medical Advisory Council. As you can see, the list is lengthy and currently includes over 100 eligible conditions. Some of the conditions listed are very specific, for example, moderate and severe asthma. Others, such as heart conditions or gastrointestinal tract anomalies are actually broad categories that include a variety of conditions within them.

Children with the following five conditions were served most frequently through the program in FFY 2004: Asthma, Cleft Lip/Palate, Diabetes, Heart Conditions, and Handicapping Malocclusion. Generally, these are also the conditions where we have paid the most for care. Other high cost conditions during that period included Genitourinary Tract Anomalies, Hearing Loss, and Seizure Disorders.

The Department is interested in discussion regarding the appropriateness of the medical and financial guidelines currently used to determine eligibility for the

Children's Special Health Services diagnostic and treatment program. Financial eligibility is currently at 185% of the federal poverty level. Families can be eligible with a cost share, similar to the recipient liability for Medicaid. However, based on telephone calls received from potential applicants, state-level staff report that one of the reasons families do not follow through with the application process is because they are over income and they believe the amount they would need to pay each month out-of-pocket is too high to be of benefit to them.

Use of the condition list to determine medical eligibility has been an area of concern. On the one hand, it concretely identifies the population to be served, provides a mechanism for rationing when finite resources are available, and includes many of the physical disabilities and chronic illnesses seen in the pediatric population. On the other hand, the list is certainly somewhat arbitrary and not all-inclusive when using the broad definition of children with special health care needs.

You will hear more about the process that is used to initiate changes to the medical condition list from Dr. Robert Wentz, Children's Special Health Services Medical Director. Ultimately, the Children's Special Health Services unit makes the final administrative decision regarding changes to the condition list after discussion occurs within the larger Department. New conditions have been added to the list over the years, although the process often takes time and careful research.

This committee also asked for specific recommendations regarding coverage. Three coverage areas have been identified: Financial eligibility, Medical eligibility, and Covered Services. Based on our needs assessment data, it is clear that out-of-pocket costs for children's medical expenses can be a burden for families. With medical eligibility, the Department recommends that Children's Special Health Services continue with the pilot study recommended by the Medical Advisory Council to see if it is a viable method to address currently

uncovered conditions. If specific conditions are still desired, other areas to consider include genetic syndromes, mental health conditions, mitochondrial disorders, and conditions leading to blindness. Lastly, the covered services that are provided could be expanded. Respite care and transportation are of particular concern but resource constraints have not allowed expansion in these areas.

We would be interested in any guidance offered by this committee. I would be happy to address any questions that you may have.