

**TESTIMONY BEFORE THE HOUSE HUMAN SERVICES COMMITTEE
REGARDING SENATE BILL 2395
FEBRUARY 28, 2005**

Chairman Price and members of the committee, I am Tamara Gallup-Millner, director of the Children's Special Health Services (CSHS) unit, which is located in the Medical Services Division in the Department of Human Services. I'm here to provide information related to SB 2395.

Work done in the CSHS unit focuses on children with special health care needs and their families. Children and youth included in this population have chronic conditions of some kind and a need for health and related services generally beyond those needed by most children. In North Dakota, about 12.4% or 19,500 children under age 18 are estimated to have a special health care need based on the definition I've just described.

Families we work with in CSHS report that having a child with special health care needs has a financial impact on their family. Some families do not have insurance, but more often, the health care coverage they do have does not meet all of their child's needs. The care that is required can become a cumulative burden when expenses are incurred year after year. Many families we hear from share the need that gave impetus to this bill.

If passed, Section 1 and 2 of SB 2395 would require CSHS to provide medical food and coverage for growth hormone treatment at no cost to individuals under age eighteen who have been diagnosed with Russell Silver Syndrome, regardless of income.

While I recognize the importance of services for all children with special health care needs and their families, including children with Russell Silver Syndrome, there are also important implications that merit attention as this bill is considered.

1. Eliminating the income eligibility requirement for treatment services through CSHS is setting a precedent that certain conditions receive preferential treatment. Families that have children with asthma, diabetes, cerebral palsy, cleft lip and palate, hearing loss, cystic fibrosis, etc., would need to meet the eligibility criteria at 185% of the federal poverty level, while those with Russell Silver Syndrome would not. The Legislature mandated the eligibility level currently used for CSHS treatment services in 2001.
2. Definitions for “medical food” and “coverage for growth hormone treatment” have not been included in the bill. These terms could be very narrowly or very broadly interpreted. For example, does the term “medical food” mean that a typical infant formula like Similac be provided, just because its concentration has been adjusted to provide more calories in order to promote adequate growth? Similac is a formula many well babies routinely use in the first year of life. Or, does “medical food” imply coverage of various formulas that are used as the primary source of nutrition for children if they require tube feedings in order to increase caloric intake? Does “coverage for growth hormone treatment” literally mean only the medication used for hormone replacement or does it include office visits, lab, x-rays, etc. needed for monitoring whether the medication is actually achieving the desired results? A clear understanding regarding the scope of covered services that are expected for children with Russell Silver Syndrome would be helpful.

3. Impact on the CSHS unit's current services and programs is possible. Although considered rare, the incidence of this syndrome is truly not known. There is currently no effective system in place to identify individuals with Russell Silver Syndrome so some caution is needed when determining the number of children in North Dakota who might receive services through this program. Projections regarding insurance status of children who would potentially be served must also be made with care. Although we did our best fiscal estimate based on information available at the time, it is unknown whether the appropriation included in this bill will be enough to meet service needs of children with Russell Silver Syndrome in the state. If more children with this syndrome are identified than projected, CSHS may need to redirect resources to this program that are currently budgeted for other services.

4. Characteristics of Russell Silver Syndrome vary widely. Some individuals have many of the documented traits associated with this syndrome, while others have very few. Required treatment may vary based on each individual's specific medical needs which may or may not be consistent with services that are included in this bill.

Section 3 directs the Department to apply for a Medicaid waiver to provide in-home services to children with extraordinary medical needs. The Department will need to determine what type of waiver would best meet the needs of the children. It could be a 1915 home and community waiver or an 1115 demonstration waiver. Based on previous experience, we estimate it will take at least a year to prepare, submit and receive approval for this type of waiver.

The fiscal note anticipates that three individuals who are not currently on the Medicaid program will take advantage of the waiver. We do recognize that a gap may exist for children who may no longer qualify for the Developmentally Disabled waiver and are not eligible for the Elderly and Disabled waiver because of the age limitation. The costs for those individuals are not included in the Executive budget.

Section 4 asks the Legislative Council to consider studying issues relating to children with extraordinary health care needs. The Department agrees that a study of this nature would be useful in determining the direction the state should follow regarding the delivery of services to this segment of our population. We would encourage SB 2395 and HCR 3054 be looked at together as both pieces of legislation address studies for children with special health care needs.

This concludes my testimony. I would be happy to respond to any questions you may have.