

**Testimony Before the Interim Budget Committee on Human Services
Children with Special Health Care Needs Study**

**Origins of the “List of Eligible Conditions” for Children’s
Special Health Services**

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In the course of recent legislative discussions about health care services for children with special health care needs, questions have arisen regarding the manner in which medical conditions become part of the “List of Eligible Conditions” for Children’s Special Health Services (CSHS). Because of the fact that I currently serve as the Medical Director for CSHS and have done so intermittently over the past 25 years, I have been asked to address this issue.

The short answer is that the “List of Eligible Conditions” has evolved in an incremental fashion in a manner that is not totally rational.

There has been difficulty in achieving agreement on what constitutes “special health care needs”. Typically these have involved conditions that tend to be chronic (i.e. lasting at least 6 months) and complex, requiring specialty care and multiple types of health care services. Care for children with special health care needs is often very expensive and may require special equipment. These children often require special educational services and therapies such as Physical Therapy, Occupational Therapy, Speech Therapy, etc.

Back in the days when CSHS was known as “Crippled Children’s Services” (CCS), the image of an eligible child was a child with a visible physical defect (“Tiny Tim”). The range of problems affecting children with special health care needs is, however, much broader, leading to abandonment of the “Crippled Children” title.

Conditions on the list fall into a number of categories. Some of them are congenital (present from birth) and may be genetic. These include “birth defects” such as cleft

palate, clubfoot deformities, heart defects and spina bifida. Some of the conditions develop later in life, such as diabetes and asthma. Some are the result of infection or injury. A category of conditions that has been recently expanding involves the so-called “metabolic disorders” such as phenylketonuria (PKU). Expansion of the number of metabolic disorders for which infants born in North Dakota are being tested has led to the need to provide coverage for treatment of these disorders.

A few of the conditions on the “List of eligible conditions” are relatively common, such as cleft palate, but many of them are extremely rare.

Many of the conditions covered by Crippled Children’s Services were visible birth defects. For a child to be eligible for diagnostic and treatment services, the child had to be “medically eligible” (i.e. have a condition on the List of Eligible Conditions as determined by the Medical Director) and meet financial eligibility requirements. Over the years, as applications for services were made for other types of health problems, these condition were brought before the Medical Advisory Council (a nine member group of health care providers who meet annually) to get their advice as to whether these “new” conditions should be added to the list. The discussions regarding possible expansion of the list have often been difficult and gut wrenching. CSHS has always had very limited financial resources and has often been viewed as a “welfare” program. Medical Advisory Council members find themselves directly involved in rationing health care. They have been hesitant to add conditions for which care is expensive or services (such as organ transplantation), which is costly. Payment for these types of services has generally been excluded. The prevalence of the condition is a factor considered by the Council, but some very rare conditions can be extremely expensive to treat. The availability of treatment for the condition has been a factor considered in the debate. While Medical Advisory Council Members try to be objective in these discussions, personal bias sometimes creeps into the debate.

There are many obvious problems with the “List of Eligible Conditions”. Many

children are excluded from coverage simply because the condition which affects them had never been brought up for discussion before the Medical Advisory Council. The fact that the Council only meets on an annual basis is a problem. Rapid advances in medical care make it difficult to keep the list current. Few health care providers have any knowledge of the list or even of CSHS as a possible resource for children under their care.

In recent years, the Medical Advisory Council has tried to wrestle with the problems surrounding the List of Eligible Conditions. Some members feel that the Medical Director should be given broader authority in determining medical eligibility. In an effort to try to make the process more rational, Tamara Gallup-Millner, Unit Director for CSHS developed a grid, which could potentially be used when evaluating potentially eligible conditions (see attachment A). We have been testing this approach recently.

Previously, CSHS staff compiled a list of potential conditions to be considered for review. The list of potential conditions came from a variety of sources. Outside parties may have requested that a condition be reviewed, or more frequently, staff added conditions to the list after screening applications that had been denied during the year. In some instances, conditions were identified based on needs assessment data. Once the list was compiled, advice was sought from the Medical Advisory Council regarding inclusion of any of the new conditions to the “List of Eligible Conditions”.

Over the last five years, the following conditions have been added to the list using this approach: Asthma, Celiac Disease, Seizure Disorders, Mucopolysaccharidosis, and conditions identified through newborn screening.

This year, the Medical Advisory Council recommended piloting use of the grid to rank currently uncovered conditions as they are received in the CSHS office. Three

physicians in the appropriate specialties would rank the condition. If the average ranking was 15-20, the condition would be considered medically eligible during the pilot period. Staff would monitor the impact of the added conditions and report back to the council at the next Medical Advisory Council meeting. Three additional conditions are currently being considered using this new approach. They include Muscular Dystrophy, severe Eosinophilic Gastroenteritis, and Wegeners Granulomatosis.

As Medical Director, I find the List of Eligible Conditions extremely frustrating. There are many conditions creating special health care needs for children in North Dakota, which are not on the list, and I feel that CSHS is not being adequately utilized as a resource of families with children with special needs. I will address my views on these issues in separate testimony before the committee.

I wish to express my appreciation to the Legislature for this study, which I feel is greatly needed.

I will be happy to address any questions you may have.

Thank you.