Providing good, coordinated care for children who have special health care needs challenges families, providers, and the health care system. The Utah 2000 Child Health Survey measured the prevalence and health status of children with special health care needs and assessed how well their needs were being met. This Health Status Update reports findings from that survey.

- Almost 90,000 Utah children (12.6%) had a chronic illness or condition and require special health care (Figure 1). Most common were behavioral conditions (31,000), asthma/respiratory (17,100), and allergies (10,100).
- The prevalence of children with special health care needs has been higher in other states (about 16%). We do not know if Utah children are healthier or if their problems are recognized less often.

**Children With Special Health Care Needs**

*Figure 1. Percentage of Utah children who had special health care needs by age and sex.*

- Most children with special health care needs were in good health, but 9% were in fair or poor health compared to only 1.8% of all Utah children (Figure 2).
- On average, children with special health care needs had 3.8 days when their physical health was “not good” and 4.2 days when their mental health was “not good” in the past month (Figure 3).
- Nearly all (96%) children with special health care needs had health insurance. Most (67%) reported less than $500 out-of-pocket expenditures for health care in the past year, but about 17% reported more than $1,000.
- Problems getting care for children with special health care needs were reported for 18% of children for medical care, 15% for dental care, and 7% for mental health care. A variety of reasons were cited for the problems (Figure 4).

**Fair/Poor Health**

*Figure 2. Percentage of Utah children with special health care needs who were in fair or poor health by sex and age.*

- Nearly all children with special health care needs reported having a usual provider for medical care or a “medical home.” These children often had more than one provider; 73% reported their provider had a thorough understanding of all the child’s care. About 9% reported the doctor had problems getting access to all the child’s medical records at least sometimes.
- Nearly all (97%) parents of these children reported they were satisfied or very satisfied with health care for their child. However, 15% of parents reported that coordination of services among providers was fair or poor.
Children were considered to have special health care needs if they had any one of these conditions, that had lasted or were expected to last for at least 12 months:

- prescription medications
- needs more services (medical, educational, mental health) than most children
- restricted activity
- physical/speech/other therapy
- mental health treatment
- durable medical equipment/special equipment
- life-threatening allergies
- special diet
- individualized education plan, early intervention, special education classes
- learning or behavioral difficulties

Children with Special Health Care Needs (CSHCN) Program

Children with Special Health Care Needs (CSHCN) is a Bureau in the Utah Department of Health, Division of Community and Family Health Services that provides special health care and related services for Utah children who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition. Many of the Bureau’s 10 programs are offered state-wide through traveling clinics. CSHCN provides direct services such as specialty evaluations and multi-disciplinary clinics, and also performs population-based interventions including universal newborn metabolic and hearing screening. The Bureau is housed in a beautiful new facility above the University of Utah campus near Primary Children’s Medical Center. CSHCN can be reached in Salt Lake at (801) 584-8284 or toll free at (800) 829-8200 or by contacting the CSHCN Case Manager at your local health department.