

# Children with Special Health Care Needs



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# Children with Special Health Care Needs (CSHCN)

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CSHCN Bureau serves children who have or are at increased risk for chronic physical, developmental, behavioral, or emotional conditions and require health and related services of a type or amount beyond that generally required by children.

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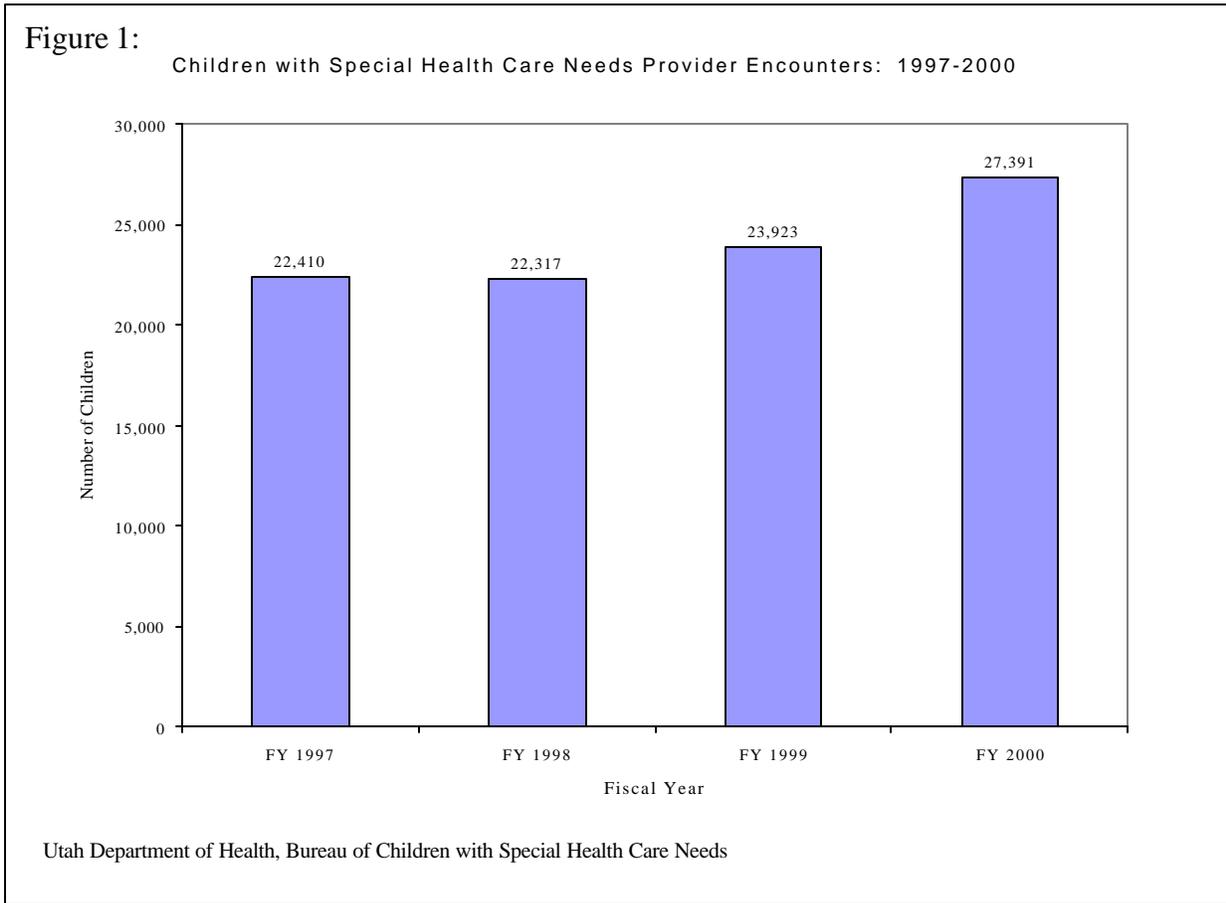


Why is it important? Infants and children with high-risk health conditions must be identified early in order to help assure that they and their families receive the care and assistance to prevent future morbidity and promote optimal development. Once identified, children with special health care needs require ongoing routine health care in their community. Ideally, providers and families will work together as partners to meet the needs of children and families.

Ongoing care is very expensive. Over time, these expenses become a great financial burden for many families. The Children's Health Insurance Program (CHIP) has begun to address the issue of lack of insurance but continues to be a major concern for CSHCN and their families. In order for services to be of value to CSHCN and their families, the system has to be organized in such a way that needs can be identified, services provided in accessible and appropriate contexts, and that there is a family-friendly

mechanism to pay for them. Family members must have meaningful, enduring, and leading roles in policy, program development, and practice. Health care services must not only be delivered in a family-centered manner, but must prepare individuals to take charge of their own health care and lead a productive life as they choose. Youth with special health care needs become adults who must be able to expect good health care, employment with benefits, and independence.

What are we doing? The purpose of CSHCN is to assure quality statewide health care for children with special health care needs and their families. CSHCN programs reduce preventable death, disability, and illness due to chronic and disabling conditions by providing access to affordable high quality health screening, specialty health care, and case management. ♦



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# Fostering Healthy Children

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Fostering Healthy Children is a program to assist in meeting the health care needs of Utah foster children. Nurses and staff from the Department of Health are co-located with caseworkers from the Division of Child and Family Services and work in partnership to coordinate the foster child's health care.

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Why is it important? Investigations over the past 20 years have highlighted the extent and seriousness of the physical and mental health problems experienced by children entering foster care.

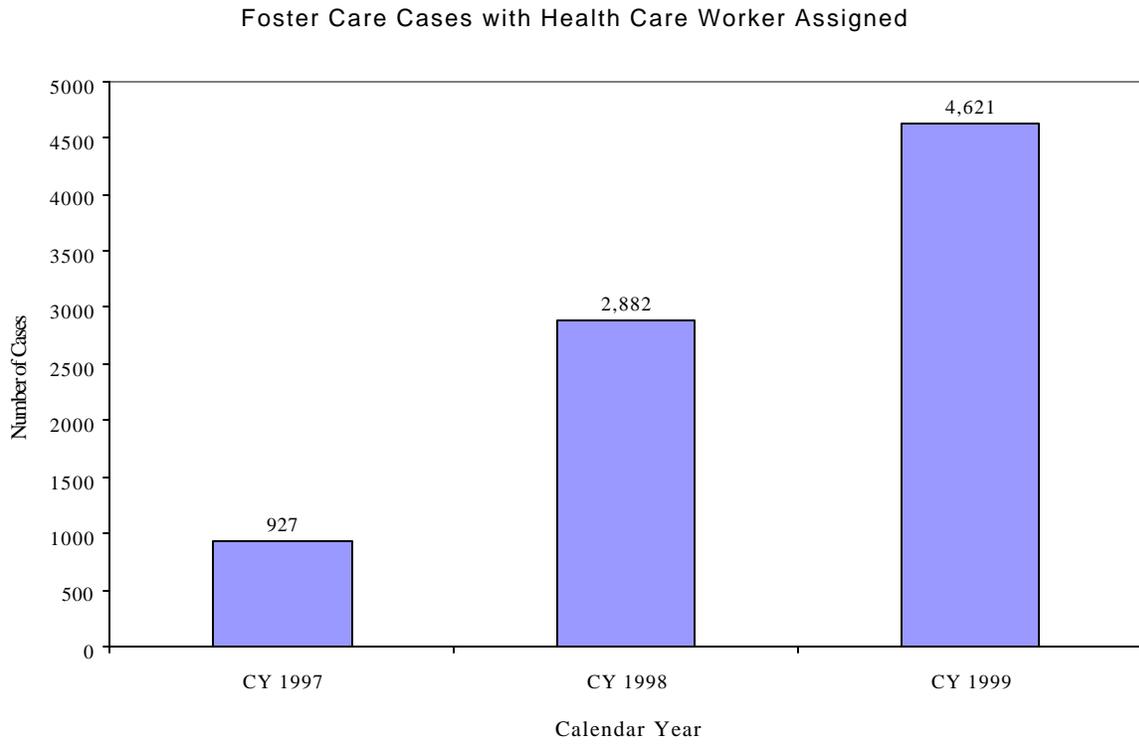
What are we doing? When a child is placed in foster care, the Fostering Healthy Children Program works with the case manager from the Division of Child and Family Services to ensure the following health care is completed:

- ✓ **Emergency Health Assessment:** This exam is required immediately if the child is a victim of suspected sexual abuse, serious physical abuse or neglect.
- ✓ **Health History:** A detailed health history about the child and family is completed within 24 hours.
- ✓ **Initial Health: Assessment:** A comprehensive physical examination is performed within 5 working days of removal from the home.

**CSHCN Mission:** To ensure the health care needs of children in the Utah Child Welfare System are met.

- ✓ **Dental Exam:** Complete dental exam including cleaning within 30 days after removal from the home.
- ✓ **CHEC (Well Child Care):** A physical examination, including anticipatory guidance immunizations and follow-up needs. Completed within 30 days after removal from the home.
- ✓ **Comprehensive Mental Health Assessment:** An assessment of the child's need for mental health services is completed within 30 days of removal from the home by a mental health professional.
- ✓ **Follow Up Care:** Any recommended treatment or services as identified by the health care provider.
- ✓ **Routine Care:** All health care services continue on at least an annual basis.

Figure 2:



Utah Department of Health, Bureau of Children with Special Health Care Needs

# Baby Watch Early Intervention

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Baby Watch Early Intervention is a statewide, comprehensive system that provides early intervention services to infants and toddlers with developmental delay or disability. The program provides early identification and developmental services for infants and toddlers, ages birth to three.

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- ✓ Strategies to build on family concerns, priorities, and resources
- ✓ Developmental services: occupational therapy, physical therapy, speech therapy, and special instruction.

Why is it important? Early intervention services are individually designed to enhance the development of infants and toddlers with disabilities and to minimize their potential for developmental delay.

How are we doing? The number of children served in the Baby Watch Early Intervention Program has been increasing ever since its beginning in 1987. In 1999, the program served a total of 5,051 children, an increase of 21% from 1998 and 41% from 1997. Efforts to find all eligible children continue at both the state and local level.

What are we doing? Some of the services offered include:

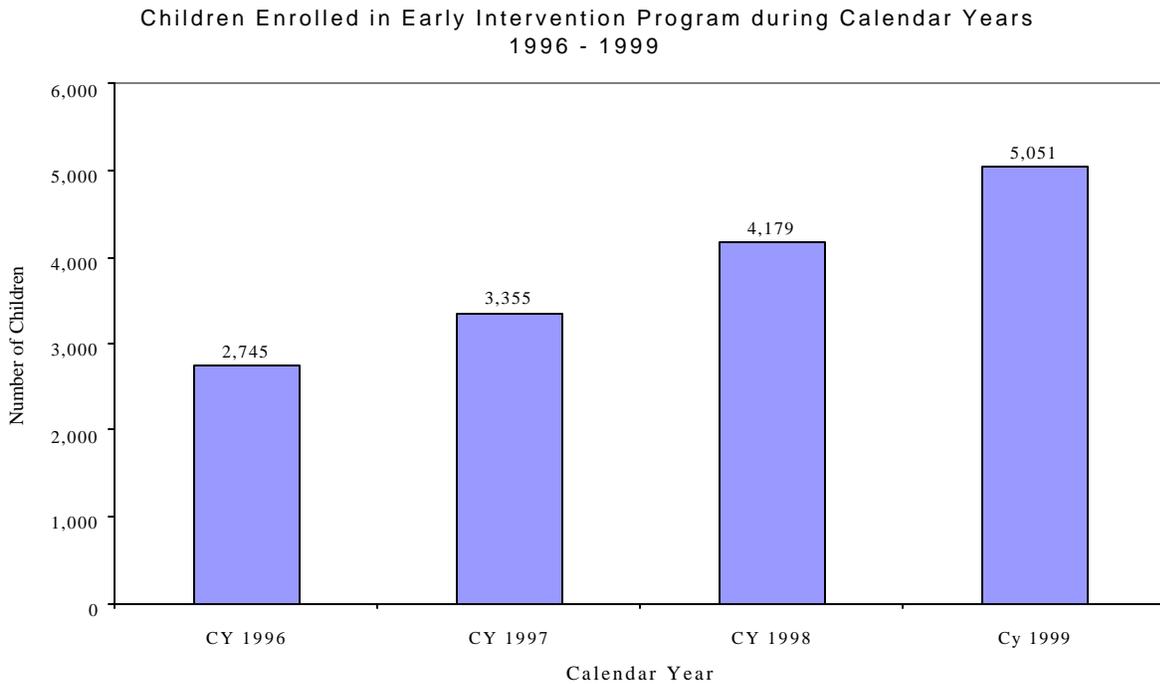
- ✓ A full assessment of a child's current health and developmental status
- ✓ Service coordination among providers, programs, and agencies

Direct early intervention services are provided in local programs funded by the Utah Department of Health. Each local program utilizes a multidisciplinary team to provide the services including special educators, nurses, nutritionists, occupational therapists, physical therapists, child development specialists, psychologists, and speech/language pathologists. Services are provided primarily in the home or other places where the child is, such as childcare settings. Two statewide programs operated by the Utah Schools for the Deaf and the Blind are also a part of the early intervention system of services.

Children are determined to be eligible for Baby Watch Early Intervention services in one of three ways:

- 1) If scores from standardized tests are greater than 2.0 standard deviations below the mean, or at or below the 2<sup>nd</sup> percentile, in one area of development; or greater than 2.0 standard deviations below the mean,

Figure 3:



Utah Department of Health, Bureau of Children with Special Health Care Needs

or at or below the 7<sup>th</sup> percentile in two areas of development; or greater than 1.0 standard deviation below the mean, or at or below the 16<sup>th</sup> percentile, in three areas of development.

- 2) Diagnosed with a physical or mental condition with a high probability of resulting in developmental delay.
- 3) The informed clinical opinion of two qualified professionals. ♦

# Hearing, Speech, & Vision Services (HSVS)

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The HSVS Program provides statewide early identification and referral of children with hearing, speech and vision problems. As a part of this effort it directs the Utah Newborn Hearing Screening Program.

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How are we doing? Utah is presently screening 92.1% of all newborns, which has improved from 78.8% in the previous year.

How does Utah compare with the U.S.? Utah is doing very well. Utah is among the top five states in the U.S. for total number of newborns screened.

Why is it important? Approximately 4-6 newborns per 1,000 have significant hearing loss. Most infants identified at birth and enrolled in appropriate early intervention services are able to maintain age level language, social and academic skills. This results in greatly reduced morbidity and ability to reach optimal potential.

What are the risk factors? There are many risk factors for hearing loss. However, universal newborn hearing screening is recommended over previously implemented high-risk programs.

## **CFHS Objective:**

By 2000, reduce the average age at which children with significant hearing impairment are identified to 6-12 months of age by promoting statewide hospital-based universal newborn hearing screening.

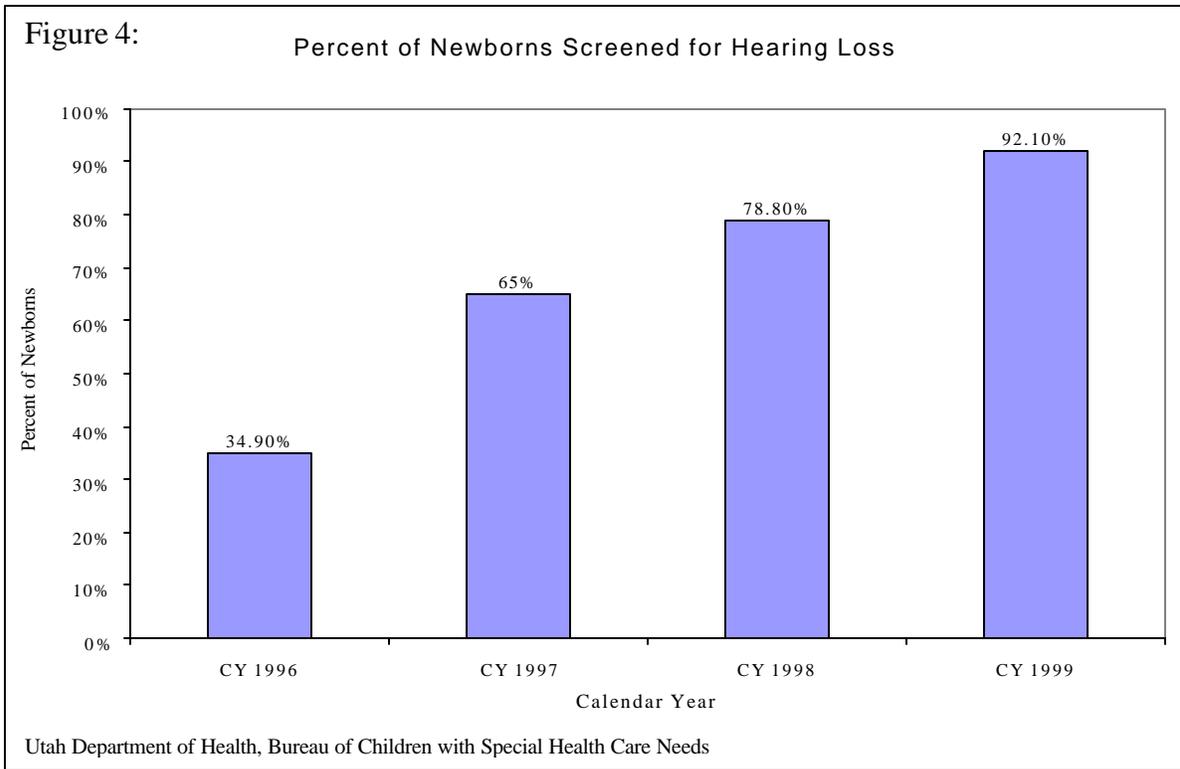
Utah baseline: 17 months in 1992.

In FY 99, increase the percentage of newborns screened for hearing loss in Utah hospitals to 90%.

Utah baseline: 58% in FY97

Recent data: 78.8% in FY99

What are we doing? Through legislation, the Utah Department of Health (UDOH) is the central data repository for universal Newborn Hearing Screening in Utah. HSVS developed and administrates the Utah Newborn Hearing Screening (NHS) Committee required by the legislation and involves representatives from pediatrics, family practice, neonatology, early intervention, private insurance, parents, and various other agencies. HSVS also developed administrative rules for the NHS Act, compiled a listing of statewide screening and diagnostic resources, and issued recommended audiologic diagnostic protocols. All hospital screening programs are required to submit their screening equipment and protocols to HSVS for approval. Monthly data reporting from birthing institutions is required by HSVS, and quarterly screening program coordinators' meetings are held at four regional sites. HSVS has ongoing coordination with the National Center for Hearing Assessment and Management for software development, technical support, training, and equipment management. A four-year



HRSA grant was awarded to HSVS on April 1, 2000 to improve the effectiveness of newborn hearing screening in Utah. HSVS provides statewide clinical services through six regional HSVS diagnostic audiology centers and twenty-two traveling clinic sites. It collaborates with other CSHCN programs, local public health offices, other public and private agencies, and local community resources. ♦

# Newborn Screening Program

## Metabolic Screening

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The Newborn Screening Program is a statewide system for early identification and referral of newborns with congenital disorders detectable by a laboratory based screening method.

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How are we doing? Utah has consistently exceeded the year 2000 objective of screening at least 95% of its newborns. All newborns that tested positive were referred for consultation and treatment.

How does Utah compare with the U.S.?

- ✓ Congenital hypothyroidism: Utah incidence rate is slightly higher at 1:2,500-3,000 births than the national rate of 1:4,000.
- ✓ Galactosemia: In Utah and the U.S., the incidence of classical galactosemia is 1:40,000-50,000 births.
- ✓ Phenylketonuria (PKU): In Utah and the U.S., the incidence is 1:10,000-15,000 in births of northern European descendants. It occurs infrequently in other ethnic groups.

Why is it important? Phenylketonuria (PKU) and other metabolic disorders have been considered the most preventable causes of mental retardation. These conditions are seen infrequently, and newborns appear normal at birth. If left untreated, symptoms

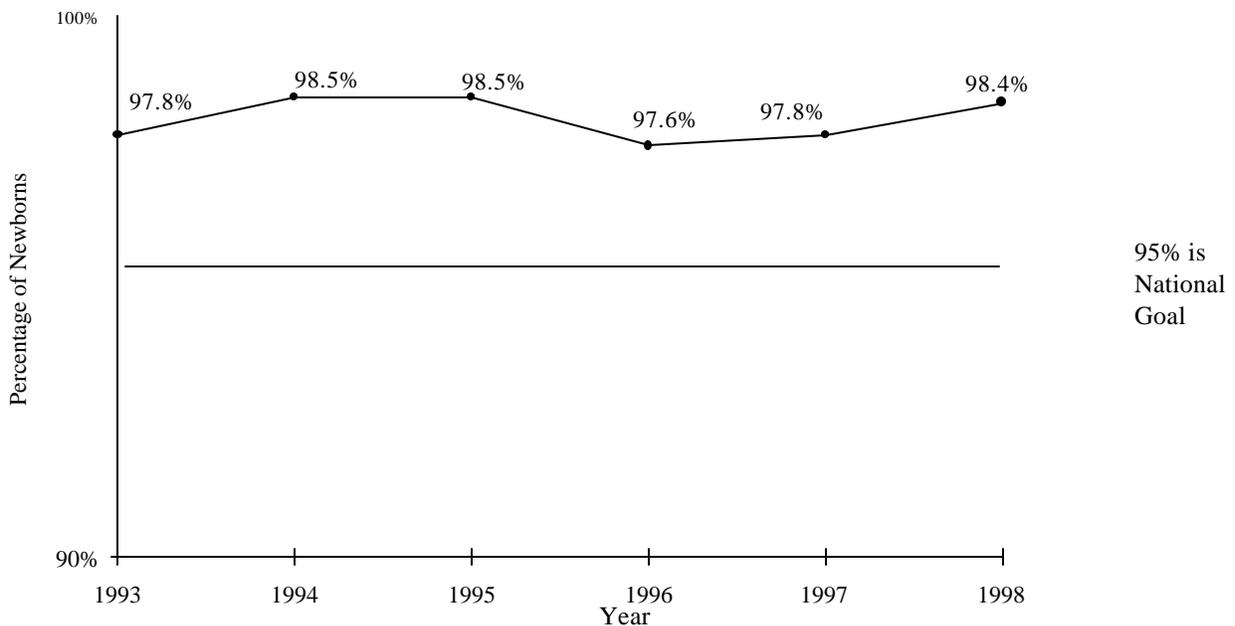
**CFHS Objective:** Exceed the year 2000 national goal that at least 95% of all newborns in Utah will be screened for phenylketonuria (PKU) and other metabolic disorders resulting in mental retardation or brain damage.  
**Utah baseline:** 98.5% of all newborns were screened in 1995  
 Recent data: 98.4% of all newborns were screened in 1998

are often seen too late to prevent permanent impairment. Untreated, phenylketonuria can result in developmental delays, seizures, and emotional disorders. Galactosemia can result in developmental delays, growth retardation, cataracts, liver dysfunction, and death if untreated. Congenital hypothyroidism results in developmental delays and growth retardation if untreated. All three of these conditions affect children of all races and ethnic groups.

What are the risk factors?

- ✓ False positive results
- ✓ False negative results
- ✓ Collection of specimen at inappropriate time
- ✓ Transfusions
- ✓ Exposure of specimen to heat or humidity
- ✓ Failure of newborn screening being performed
- ✓ Institutions of birth not obtaining a specimen
- ✓ Home birth
- ✓ Lack of education of provider and family
- ✓ Receipt of un-testable specimen
- ✓ Lack of education of phlebotomist
- ✓ Poor collection technique
- ✓ Delay in sending specimen

Figure 5: Percentage of Newborns Screened for Metabolic Disorders\*, Utah, 1993-1998



\*Disorders include congenital hypothyroidism, galactosemia, and phenylketonuria (PKU)  
 Source: Utah Department of Health, Division of Community and Family Health Services

What are we doing? The Newborn Screening Program will continue to coordinate the screening efforts throughout the state of Utah. Newborn screening collection kits will be updated and sold to all institutions of birth and lay midwives. Consultations with all providers are available by phone or by site visit. Inservices will be offered to institutions of birth, health care providers, clinics, and lay midwives. ♦

