

CHILDREN WITH SPECIAL HEALTH CARE NEEDS



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Bureau Director

MCH Pyramid of Health Services



Infrastructure Building

CHARM

Child

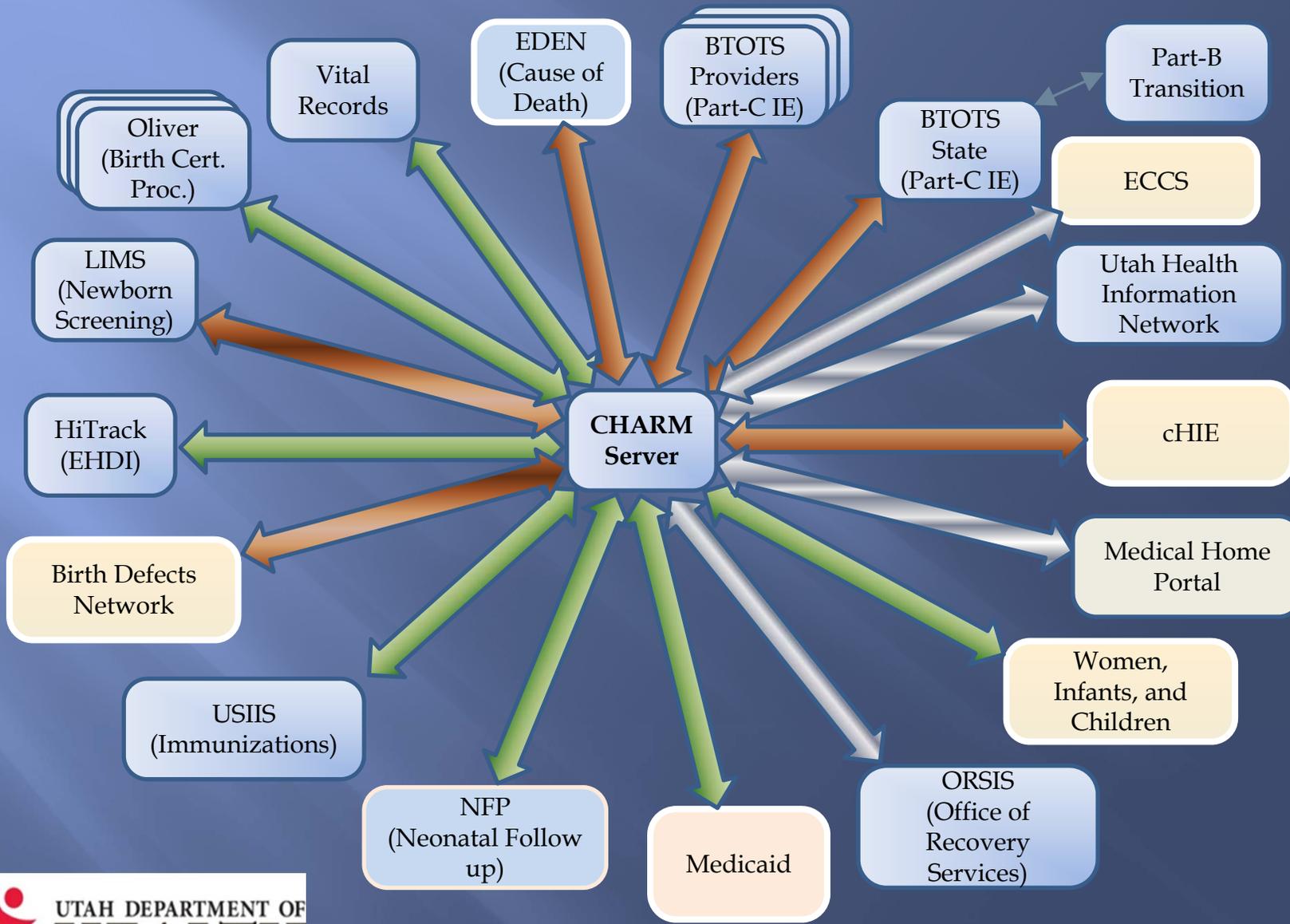
Health

Advanced

Records

Management





Infrastructure Building

URLEND

- ▣ Utah Regional Leadership Education in Neurodevelopmental Disabilities
 - Long term interdisciplinary leadership
 - Collaborative Program with :
 - ▣ University of Utah
 - ▣ Utah State University
 - ▣ CSHCN Bureau

Infrastructure Building

Autism Treatment Account

- ▣ 2 year pilot program
 - Funding
- ▣ ABA therapy for children between 2 and 6
- ▣ 26 children are currently receiving therapy

Population Based Services

Newborn Screening



Newborn Screening Program 2012 Stats

- ▣ 99% newborns screened
- ▣ 4% or ~1,800 abnormal 1st NBS
- ▣ 1.1% or ~600 abnormal 2nd NBS
- ▣ .8% confirmatory testing ~340
- ▣ <1% diagnosed with disorder
 - 293 confirmed diagnosis

Diagnosis by Disorder	%
Amino Acid / Fatty Acid / Organic Acid (enzyme defic.)	6%
Biotinidase deficiency	<1%
Congenital Adrenal Hyperplasia (CAH)	2%
Congenital Hypothyroidism	7%
Cystic Fibrosis	7%
Galactosemia	<1%
Hemoglobinopathies	72%

SCID - July 1, 2013



- ▣ Severe Combined Immunodeficiency Disease

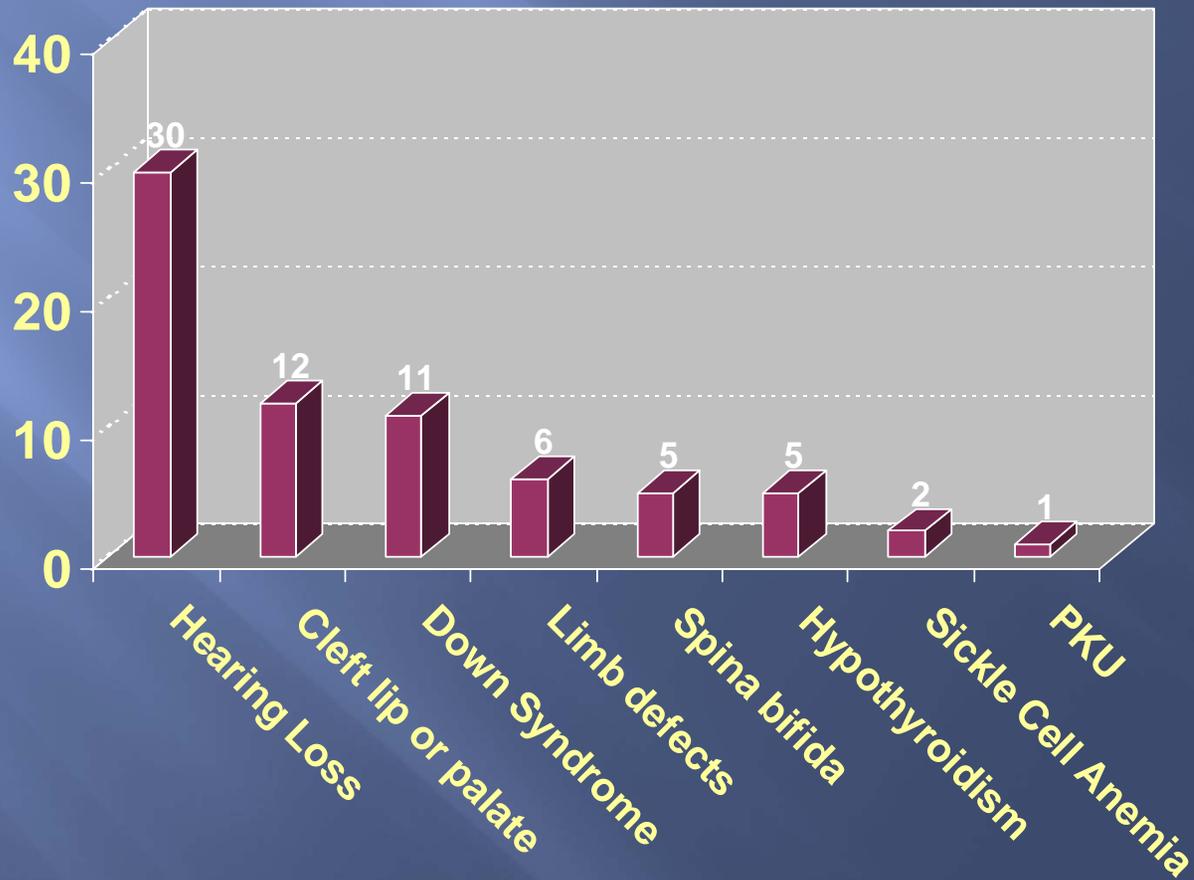


Population Based Services

Newborn Hearing Screening



Hearing loss occurs more frequently than any other condition for which population-based screening is done.











Spring is my favorite season. The sun shines bright. The flowers begin to grow. I like spring.







Newborn Hearing Screening 2012 Stats

- ▣ 98.1% newborns screened
- ▣ 4.7% failed first screen (2,412)
- ▣ 478 failed second screen / referred for dx
- ▣ Infants with normal hearing: 133
- ▣ Infants with permanent hearing loss: 83
- ▣ In process: 252 (LTFU: 10)
 - Goal: 1 - 3 - 6

Legislative Updates

- ▣ HB 81 CMV Health Initiative
 - Public Education
 - Referral for CMV testing after 2nd NBHS

- ▣ HB 276 Screening for CCHD
 - Pilot
 - ▣ determine screening cutoff points and effectiveness (pulse oximetry)
 - ▣ develop implementation plan
 - ▣ develop training materials



Enabling Services

▣ Technology Dependent Waiver

- ▣ Waivers allow states greater flexibility in providing services to people living in community settings
- ▣ A limited number of individuals are served: 120
 - (+10 with Medicaid Caseload growth)
- ▣ Current Waiting List: 60
- ▣ Who Qualifies?



Enabling Services

Fostering Healthy Children



- ▣ 1994 - National Center for Youth Law

vs.

State of Utah & the Division of Child and Family Services (DCFS).

- ▣ Safety and well-being of children in foster care not being met.
- ▣ Settlement agreement included nursing oversight.

Legislative Update

▣ HB 157 Children's Hearing Aid Pilot Program



- Funding
- Ages Served

Direct Services

Neonatal Follow-up Program

- ▣ Provides developmental screening to NICU graduates who meet following criteria:
 - ≤ 1250 grams birth weight (~ 2 lbs 12 oz), and/or
 - ≤ 26 weeks gestation, or
 - Diagnosis of hypoxic ischemic encephalopathy
 - ECMO support in NICU

▣ Multidisciplinary team which includes:

- Developmental pediatrics
- Nursing
- Psychology
- Speech pathology
- Audiology
- Ophthalmology
- Nutrition
- Occupational/Physical therapy
- Neurology (Provo site only)
- Social work (Ogden site only)



- ▣ Clinics are held each month in:
 - Salt Lake City (CSHCN building)
 - Ogden (USBD)
 - Provo (Utah County Health and Justice Bldg)



McKenzie, 4 ½ years
26 week, 945 grams

Direct Services

Developmental Consultative Services

Child Development Clinic

- Birth to 7 years for children with special health care needs such as:
 - medical/physical challenges
 - developmental delays
 - ASD, ADHD, speech/language disorders, etc.
 - associated emotional/behavioral difficulties

Direct Services

Specialty Services

- ▣ Provides services to all CSHCN clinics
 - ▣ Screening diagnosis and referral
 - Physical Therapy
 - Occupational Therapy
 - Audiology
 - Speech-Language Pathology
 - Transition Services / Case Management

Itinerant Clinics

Development consultations for children birth to 18 years are provided by multidisciplinary teams, which travel to 7 sites across the State.

CSHCN Satellite clinics are conducted in the following cities:

- ▣ Moab
- ▣ Blanding/Montezuma Creek
- ▣ Ogden
- ▣ Price
- ▣ Richfield
- ▣ St. George
- ▣ Vernal



Other Clinics

- ▣ Osteogenesis Imperfecta Clinic
- ▣ Cerebral Palsy Clinic
- ▣ Prader Willy
- ▣ Genetics Clinic
- ▣ South Main Clinic
- ▣ Cranio-facial Clinic
- ▣ Orthopedics
- ▣ Mentoring and Training



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Population Based Services /
Enabling Services

Utah Registry of Autism and
Developmental Disorders
(URADD)

The Utah Birth Defect Network
(UBDN)

- ▣ Statewide surveillance systems

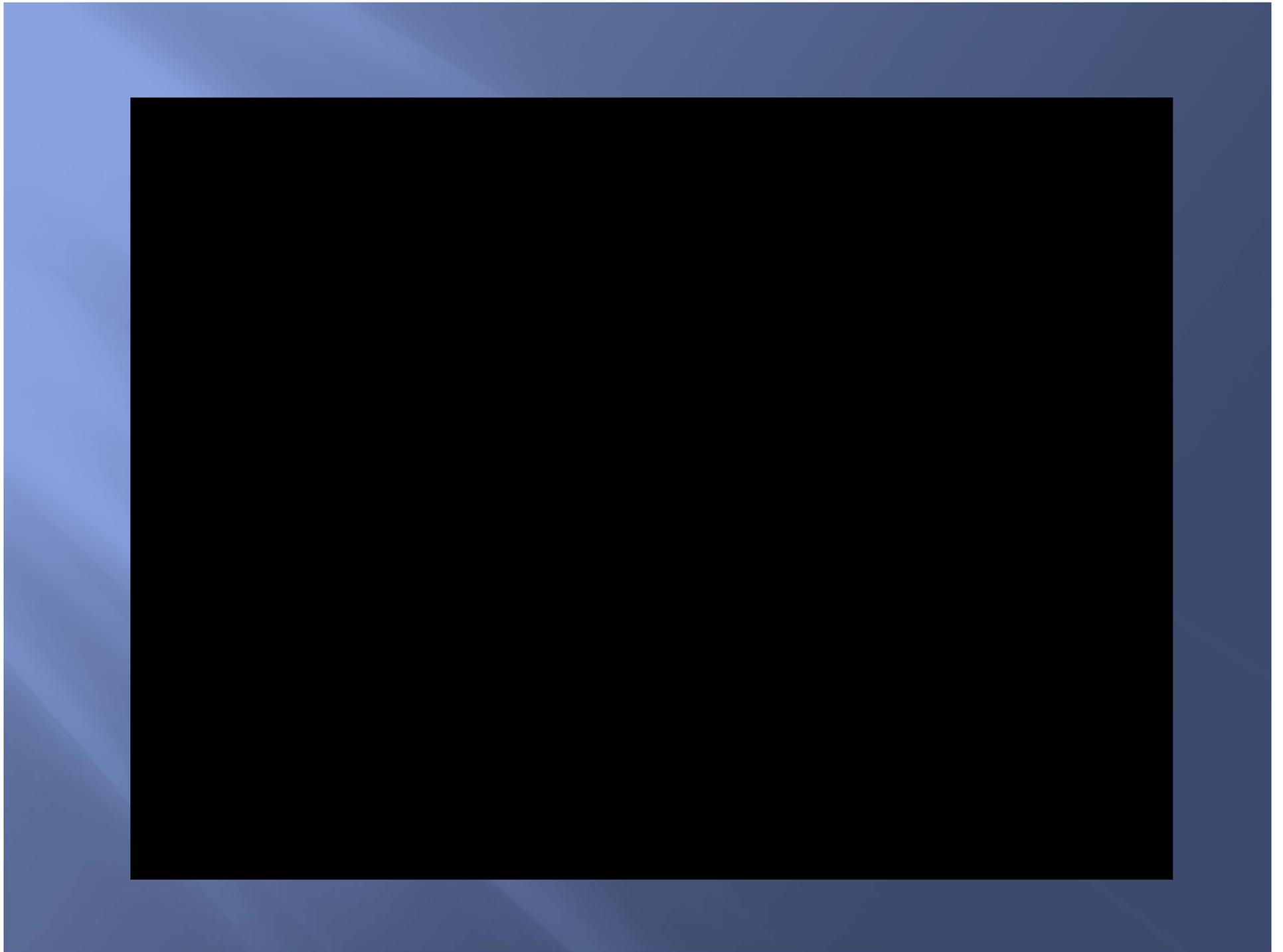
- ▣ **UBDN** tracks all major structural malformations in children born to Utah mothers

- ▣ Surveillance data is used to assess
 - Trends over time
 - Cluster investigation
 - Impact of prevention efforts
 - Support research opportunities

Prevention: Neural Tube Defects & Folic Acid

- ▣ Folic Acid Educational Campaign
- ▣ NTD Recurrence Prevention
 - UBDN recurrence packet





Questions?



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