

A collection of historical artifacts is displayed on a light-colored surface. On the left, a portion of a wooden chessboard with a checkered pattern and several chess pieces is visible. Next to it are two ornate medals with star-shaped centers and intricate designs. A red ribbon with a circular emblem is also present. In the bottom left corner, there is a circular compass with a needle and directional markings. A pair of round, gold-rimmed glasses with thin temples is positioned in the center of the image.

Primary Care Issues for Pediatric Patients

Women's and
Children's Health
Section

Children and Youth
with Special Health
Care Needs



Children and Youth with Special Health Care Needs (CYSHCN)

“Children with special health care needs are those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.”



Leadership, Assessment, and Assurance

The Women's and Children's Health Section is vested with the responsibility to facilitate the development and planning of community based systems of services for children and youth with special health care needs and their families.

Assessment





Child Health Assessment Monitoring Survey (CHAMP)

- ◆ 1% of parents reported child has high blood pressure
- ◆ 0.6% reported child has high blood sugar or diabetes
- ◆ 13.1% of parents report child uses or needs more medical care than is usual for most children of the same age

(Total births 2005: 123,040)



Birth Defects Monitoring Program

2002 Total Births = 117,307

North Carolina

ICD Codes Related to Kidney Disease

7530 Renal agenesis & dysgenesis

7531 Cystic kidney disease

7532 Obstructive defects of renal pelvis & ureter

7533 Other specified anomalies of kidney



2002 Counts (for the 4 ICD codes mentioned)	
White non-Hispanic	289
Black non-Hispanic	124
Hispanic	79
Native American	3
Other/unknown	11
Total	506

Note: Counts displayed are per defect. One child may have more than one birth defect.

Source: State Center for Health Statistics, North Carolina.



NC and U.S. ESRD (Dialysis) Prevalence Rates for 2004

- ◆ 0-4 years of age: 36.4 (U.S. rate 25.4)
- ◆ 5-14 years of age: 132.2 (U.S. rate 136)
- ◆ 15-24 : 436 (U.S. rate 492.5)

(rates are per million population)

Source of data: Southeastern Kidney Council



NC 2005 ESRD (Dialysis) Rates

For ages 5-24 years of age:

Incidence 30.9 per million persons

Prevalence 72.7 per million persons

Source of data: Southeastern Kidney Council

A collection of military medals and a pair of glasses are arranged on a light-colored, textured surface. On the left, a blue ribbon with a circular emblem is visible. Below it is a large, ornate silver star-shaped medal with a central emblem. To the right of this is another similar star-shaped medal, but smaller and less ornate. A pair of gold-rimmed glasses with thin temples is positioned horizontally across the center. In the bottom left corner, a circular compass rose is partially visible. The background is a plain, light-colored surface with a subtle texture.

Assure or Provide Care



Local Health Departments

- ◆ About 40 provide pediatric primary care
- ◆ The remainder must refer to a source of primary care in the community if they do not provide primary care
- ◆ The majority still provide well child care services (immunizations, periodic exams, screenings, etc.) to many uninsured, Medicaid, and Health Choice children



Health Check Outreach: NC Medicaid For Children

- ◆ Linkage of children birth to 21 years of age to an ongoing source of primary care and medical home in their community
- ◆ Promotion of Early Periodic Screening, Diagnostic, and Treatment (EPSDT) which requires periodic screening, vision, hearing, and dental services during periodic exams
- ◆ EPSDT also requires a BMI as age appropriate, BP beginning at age 3, urinalysis at age 5 years and during periodic exams for all sexually active youths



Section 1905 (a)

“EPSDT requires Medicaid to cover services, products, or procedures for Medicaid recipients under 21 years of age if the service is medically necessary health care to correct or ameliorate a defect, physical or mental illness, or a condition (health problem) identified through a screening exam (includes any evaluation by a physician or other licensed clinician).”



Section 1905 (a) (cont.)

“This means that EPSDT covers most of the medical or remedial care a child needs to improve or maintain his/her health in the best condition possible, compensate for a health problem, prevent it from worsening, or prevent the development of additional problems.”



Children's Special Health Services (CSHS)

- ◆ Fund for NC Medicaid eligible children birth to 21 years of age with certain chronic health conditions
- ◆ Provided some over the counter medications, formulas, supplies, and equipment, etc. that are not covered in the Medicaid state plan
- ◆ Changes in the program coming due to EPSDT and new Medicaid policy



Health Choice Outreach

- ◆ State Children's Health Insurance Program (SCHIP) – about 109,000 children 6-18 years of age
- ◆ Benefits package equivalent to State Employee's Health Plan
- ◆ Special needs package with additional services that the Medicaid state plan covers



Genetics

- ◆ Genetic consultants staff regional clinics with geneticists
- ◆ Children are evaluated for genetic conditions and syndromes
- ◆ Families and children are counseled about the chances of CKD for that child and other family members as appropriate



Children With Special Health Care Needs Help Line

Provides information about Medicaid, Health Choice, and other state and community resources for families and providers related to children with special health care needs.

1-800-737-3028



Child Service Coordination

- ◆ Serves children at risk for or with chronic health conditions such as CKD
- ◆ Provides a strengths and needs assessment of families and children
- ◆ Connects families to resources and other services in the community
- ◆ Available in most counties



Early Intervention

- ◆ Can serve children with CKD who currently meet developmental delay criteria
- ◆ Could serve those with one or more congenital or genetic conditions related to CKD that have developmental implications for the future



Medical Nutrition Therapy

- ◆ Can be provided through Medicaid in health departments or Children's Developmental Service Agencies for children with a variety of chronic conditions
- ◆ Includes assessment and ongoing care by a registered dietician
- ◆ Policy changes proposed to CMS by Medicaid



Transition of Youth With Special Health Care Needs

- ◆ Carolina Health and Transition (CHAT) project to develop a curriculum about the transition of YSHCN from pediatric to adult health care for youths, families and providers
- ◆ Statewide interest and other complementary efforts
- ◆ Implementation in primary and specialty care
- ◆ Capacity building



What is transition?

- Transition is the deliberate, coordinated provision of developmentally appropriate and culturally competent health assessments, counseling, and referrals.
- The goal is to ensure successful transition to the adult health care system, work, independence, and inclusion in community life.

(HRTW April 2007)




Medical Home Demonstration Projects

Ongoing assessment and improvement in the ways/processes in which primary care professionals and/or specialists partner with families to direct or provide quality and cost-effective care that is comprehensive, coordinated, continuous, family-centered, accessible, culturally effective, and compassionate to CYSHCN.



Medical Home Demonstration Products

- ◆ Use of complexity scoring to develop a registry of CYSHCN
- ◆ Use of care coordinators (i.e. for pre-visit contacts)
- ◆ Some data that shows effects on ER use, hospitalizations, and after hours use
- ◆ Relationships built with multiple community resources
- ◆ Office policies, efforts, and systems that promote family-centered care

A collection of historical artifacts is displayed on a light-colored surface. On the left, there is a wooden board with a grid of small, round, light-colored buttons. A red ribbon with a white star-shaped medallion is pinned to the board. Below it, a blue ribbon with a white star-shaped medallion is also pinned. A pair of round, gold-rimmed glasses with thin temples lies on the surface. In the bottom left corner, a circular compass with a white face and black markings is visible. The text "Another Statewide Effort: Improving Pediatric Access Through Collaborative Care (IMPACC)" is overlaid on the right side of the image in a black, serif font.

Another Statewide Effort:
Improving Pediatric
Access Through
Collaborative Care
(IMPACC)



Improving Pediatric Access Through Collaborative Care

- ◆ Initiative with Community Care of NC, DMA, Duke Endowment, and six pediatric tertiary medical Centers
- ◆ Care coordinators in one to three outpatient clinics at each center
- ◆ Work with medical homes and specialty clinics to improve communication and management of patients
- ◆ CMC and UNC will have a part time or full time care coordinator for the nephrology clinics



Needs

- ◆ A medical home for every child with special health care needs
- ◆ More care coordination for children with special health care needs
- ◆ More resources/options for the uninsured and underinsured with chronic conditions
- ◆ Enrollment of more children eligible for Health Check or Health Choice



Needs (cont.)

- ◆ Spread of quality improvement in primary and specialty care for CYSCHN across the state
- ◆ More education about the process of transitioning youths from pediatric to adult health care
- ◆ Mentoring and adequate reimbursement to allow more adult and pediatric primary care providers to care for youths with complex conditions such as CKD




And More Needs...

- ◆ More funding and staff to address the needs of CYSHCN
- ◆ Strategic planning across agencies to set common goals
- ◆ Use of universal communication principles to address low health literacy



Strengths

- ◆ Many stakeholders with interest in CYSHCN
- ◆ Strong family and provider champions in NC
- ◆ EPSDT/ Section 1905 (a)
- ◆ Interest in quality improvement in primary health care – CCNC, IPIP, Bridges to Excellence, component of board recertification
- ◆ Statewide interest in transition

A collection of military medals and a compass are displayed on a wooden surface. The medals include a red ribbon with a circular emblem, a blue ribbon with a circular emblem, and two silver Maltese crosses with central emblems. A pair of gold-rimmed glasses and a small brass compass are also visible.

Thank you!
Any questions???

Monique.winslow@ncmail.net

Gerri.mattson@ncmail.net