



NC Health and Transition (CHAT)
Outgrowing Pediatrics
Medical Care in Emerging Adulthood

NC Institute of Medicine Task Force
November 19, 2008

Learning Objectives

- Learn who YSHCN are and what they need to make the successful transition from pediatric to adult health care systems
- Understand what is meant by health care transition and why it is an important outcome
- Introduce Carolina Health and Transition (CHAT) project
- Identify data to support need for health care transition activities in NC
- Track CHAT activities to date and upcoming plans

C/YSHCN: Who are They?

“**Children and youth** 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.”

Source: McPherson, M., et al. (1998). A New Definition of Children with Special Health Care Needs. *Pediatrics*. 102(1);137-139.

<http://www.pediatrics.org/search.dtl>



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Health Care Transition: A Definition

- The purposeful, planned and timely transition from child and family-centered pediatric health care to patient-centered adult-oriented health care
- A **process**, not a single event
- Contributes to assuming adult roles and functions (along with social and educational transitions)

Transition from child-centered to adult health-care systems for adolescent with chronic conditions.
A position paper of the Society for Adolescent Medicine. J Adolesc Health. 1993; 14:570-576



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The Goal of Health Care Transition

Maximize lifelong functioning and potential through the provision of high quality, developmentally appropriate health care services that continue uninterrupted as the individual moves from adolescence to adulthood

AAP, AAFP, ACP-ASIM: Consensus statement on health care transition for young adults with special health care needs. *Pediatrics* 2002;110:1304-6



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Why is Transition Important?

Youth with special health care needs will receive the services necessary to make transitions to all aspects of adult life, including adult health care, work, and independence.

*SOURCE: BLOCK GRANT GUIDANCE
New Performance Measures See p.43
<ftp://ftp.hrsa.gov/mchb/blockgrant/bggguideforms.pdf>*

Youth With Disabilities Stated Needs for Success in Adulthood

A Study by the PACER Center
(Parent Advocacy Coalition for Educational Rights)

PRIORITIES:

1. **Career development** (develop skills for a job and how to find out about jobs they would enjoy)
2. **Independent living skills**
3. **Finding quality medical care**
4. **Legal rights**
5. **Protect themselves from crime**
6. **Obtain financing for school**

Problem

- Increased survival rates for YSHCN mandate a greater emphasis on the transition process, particularly as it relates to health care systems and services.
- The number of YSHCN (aged 12-17) is steadily increasing. In 2001 population of YSHCN (ages 12-17) was 14% and this population increased to 18.4% in 2005/2006.
- According the CSHCN national survey, there are approximately 734K youth (12-17) with special health care needs.

Problem

- 57% of NC families of YSHCN reported a lack of satisfaction with partnering with their health care provider. 2005 SLAITS Survey
- NC ranks below the nation (39% vs. 41%) in the percent of YSHCN who receive the services necessary to make appropriate transitions to adult health care. 2005 SLAITS Survey

	Overall	Urban core	Suburban	Large town	Small town/ Rural
	% Est. # CSHCN	% Est. # CSHCN	% Est. # CSHCN	% Est. # CSHCN	% Est. # CSHCN
NC	39.9 49,678	42.2 30,871	29.8 3,799	43.0 10,635	31.5 4,373

Discussing transition with doctors and other providers

-- CSHCN ages 12-17 yrs only North Carolina

Discussion not needed -- youth's doctors treat adults and children	No, have not talked about it	Yes, we have talked about it
38.7	48.4	12.9
50,773	63,417	16,956

Talked with family about how to maintain youth's health insurance as he/she becomes an adult

-- CSHCN ages 0-17 only North Carolina

No Was Not Discussed	Yes Was Discussed
78.9	21.1

YSHCN are Talking

Main concerns for health:

PACER Survey - 1300 YOUTH with SHCN / disabilities

- 1. What to do in an emergency,**
- 2. Learning to stay healthy***
- 3. How to get health insurance*,**
- 4. What could happen if condition gets worse.**



SOURCE: Joint survey - Minnesota Title V CSHCN Program and the PACER Center, 1995

*SOURCE: National Youth Leadership Network Survey-2001



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Carolina Health and Transition (CHAT)

■ Funding Source

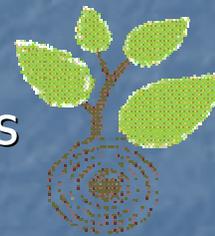
- HRSA
- 3 year grant (May 1, 2006-April 30, 2009)

■ Purpose:

- To assure that children and youth with special health care needs (C/YSCHN) receive coordinated, comprehensive care within a medical home & needed services to make the transition to adult health care systems

■ Objectives

- Development of a Health Care Transition Materials
- Education and Mentoring
- Evaluation and Dissemination
- Collaborative Health Promotion



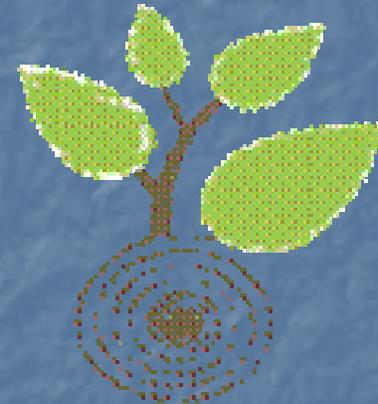
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Who is CHAT?

- **3 Primary Initiatives**
 - Youth (ADA-CIL)
 - Family (ECAC)
 - Providers (MAHEC)
- **2 Supporting Initiatives**
 - Youth mentor/leadership (CDL)
 - Care coordination
- **1 Program Evaluation**
 - Survey development, Database design (UNC-G)



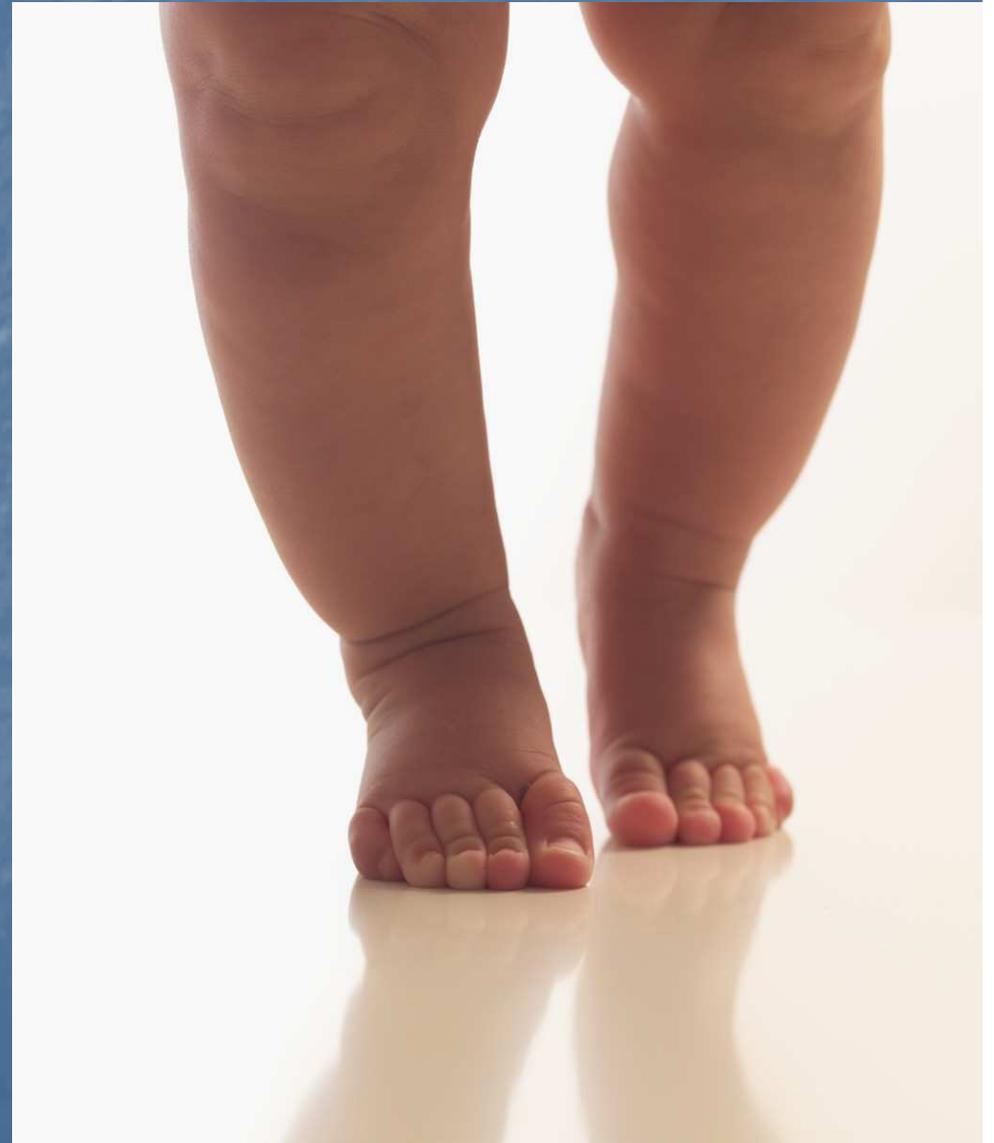
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The Growth of CHAT

Taking Baby steps



So Far...

- **Materials Development**
 - Developed logo, manuals, health care transition training materials
 - Youth health care transition video and other resource materials
 - Completed evaluation manual and survey instruments to measure and monitor progress
 - Offer CME for medical providers

- **Implementation**
 - Ongoing piloted individual workshops with youth, families, medical providers
 - Initiated combined implementation with youth, families and providers
 - Started youth leadership and advocacy workshops
 - Materials implemented with UNC Kidney Center

- **Systems Integration/Partnership Development**
 - **NC Health Care Transition Conference - Most recent (Nov 15-16, 2008)**
 - NC Interstate Mini-Summit for Adult and Pediatric Providers (Jan 2008)
 - Received endorsements from NC Pediatric Society, NC Academy of Family Medicine, UNC Centers for Development and Learning
 - Engaged and strengthened university and community-based partnerships



CHAT Next Steps...

- **Development of Materials/Resources**
 - Website development
 - Finalize CHAT training/leadership materials
 - Develop fact sheets and patient education brochures
- **Implementation**
 - Linkage with QI activities (Carolinas Medical Center)
 - Expand use of materials by partner agencies
 - Distribute materials through school system (e.g. school nurses, SBHC, child/family support teams, OES)
 - Continue to monitor and evaluate progress

CHAT More Steps

■ Systems Integration

- Integration with existing initiatives (e.g. ICARE, CCNC, IMPACC)
- Partner with hospitals, adult care providers, youth/family councils
- Merge with medical home funded project activities (e.g. NC Pediatric Society)

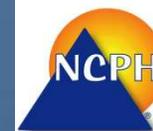
■ Sustainability

- Coordinate/Facilitate linkage of medical home and health care transition activities in NC
- Development of state plan
- Collaborate with stakeholders to identify sources of public/private funding
- Support ongoing initiatives to promote health care transition for youth with developmental and intellectual disabilities



Barriers

- **Systemic**
 - Availability of family and internal medicine physicians
 - Insurance reimbursement for transition services
 - Fragmentation of primary and specialty adult health care services
- **Structural**
 - Knowledge about referral networks
 - Consumer and Parent Education
 - Medical Training in transition planning, chronic care management and developmental disabilities for Young adults with complex medical issues
- **Psychosocial**
 - Communication between youth, families and providers
 - Difficulty breaking bonds with families and providers
 - Youth self-advocacy and health management skills



Contact Information

For more information about CHAT:

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