Health Care Transition

A Parent, Family and Caregiver's Guide

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The N.C. Family to Family Health
Information Center

A project of The Exceptional Children's
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Carolina Health and Transition (CHAT)
The North Carolina Division of Public Health
Women and Children's Health Section
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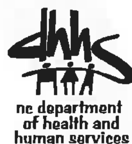

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Introduction

CHAT | Carolina Health and Transition Project

A federally funded project through the NC Division of Public Health, Children and Youth Branch.

Purpose: To ensure that children and youth with special health care needs receive coordinated, comprehensive care within a medical home and the needed services and supports to make the transition to adult health care systems.

The CHAT project targets barriers in the availability of, and access to, quality health care services by broadening awareness, teaching specific skills and changing systems of practice for Youth with Special Health Care Needs (YSHCN), their families and medical providers. Activities of the CHAT project build upon and link with other state-wide initiatives designed to improve health care opportunities and practices for all children, by including issues specific to transition and medical home in medical care for YSCHN.

Three Initiatives

Youth

Goal: To increase the number of YSHCN who have the skills needed to successfully transition from pediatric to adult health care systems within a medical home.

Family/Parent

Goal: To increase the number of families parenting YSHCN who have the skills to support self-management and healthy behaviors, advocate for their youth's transition, and find adult providers with the skills to support transition within a medical home.

Health Care Providers

Goal: To increase the number of medical providers who have knowledge and expertise in providing quality medical services to YSHCN and who are able to support the transition from pediatric to adult health care systems within a medical home.

Goals of This Handbook

This handbook will help you:

- Understand the importance of health care transition
- Identify barriers to health care transition
- Learn about the medical home concept related to health care transition in North Carolina
- Identify the skills necessary for successful health care transition
- Learn how to develop a portable medical summary
- Be able to discuss a health care transition plan with your child's medical provider
- Be able to discuss partnering strategies with providers to support the health care transition process
- Identify insurance issues related to health care transition
- Realize that it is acceptable to ask questions of your child's provider if something is said or written that you do not understand
- Share advocacy skills to pass on to your child to increase their self-management of health care
- Identify resources to help you and your child with the transition process
- Learn how to identify sources of support as well as how to mentor other parents as they experience transition with their child

Chapter 1

Introduction to Health Care Transition

Chapter 1 What is Transition?

There are many transitions in life:

- School
- Work
- Independence
- **Health**

Our focus is on **health care transition** which involves the movement from pediatric to adult health care systems, with a primary focus on youth with special health care needs.

Keys to Understanding Health Care Transition

Health care transition is…

- **a process:**
  - Different from **transfer** of care which is an *event*
  - Requires preparation and planning
  - Occurs in phases
- **individualized:**
  - One size does not fit all
  - Movement from one phase to the next depends on when the individual youth is developmentally ready
  - Timing of transition may be different for youth depending on their needs

Why Understanding Health Care Transition for YSHCN is Important

Transition realities for YSHCN

- 90% of YSHCN reach their 21st birthday
- 45% of YSHCN lack access to a physician who is familiar with their health condition
- 30% of 18- to 24-year-olds lack a payment source for needed health care
- Many youth lack access to primary and specialty providers[1]

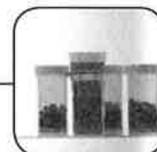
The importance of health care transition

YSHCN should understand that addressing their health needs first and foremost is the key to having a more productive life as an adult. ***Health care transition*** is an important process that helps youth develop the necessary skills that can lead to positive health outcomes.

Successful health care transition is related to:

- Better health as an adult
- Self-sufficiency and independence
- Prevention of secondary conditions
- Decreased emergency room use and overall medical costs

Health care self-management skills



Health care self-management skills are related to the youth's ability to manage their own healthcare. By learning these important skills, YSHCN will have greater confidence in managing their health issues as an adult.

Some of these health management skills include:

- Scheduling appointments with health care providers (who to see and when)
- Medication management (what, why, when and how)

- Record keeping and documentation
- Medical decision making (especially if your child is now 18 years old)
- Knowledge of health condition
- Knowledge of insurance options

Potential Barriers to Health Care Transition

Even with increased awareness of the importance of health care transition, there are many YSHCN that are still not prepared to take responsibility of their own health needs as they enter adulthood. There are often barriers that prevent youth from receiving the necessary services to support a smooth transfer to the adult health care provider. These barriers are broken down into 3 categories: 1) personal; 2) service; and 3) structural.

Personal barriers (Individual factors)

Youth

- Fear, anxiety, sense of loss or risk with transfer to an adult provider
- Supporting choice of healthy life styles
  - Diet
  - Exercise
  - Safety
- Relationships
  - Sexuality
  - Preparing for parenthood
- Progression of health concerns

Family/Caregiver

- Ability to support and to let go
- Family members working together toward a common goal
  - Agreement and support among caregivers

- Trust that your young adult can manage his/her own health care
  - ➤ Having input without interfering with doctor/patient relationship (between youth and doctor)

Service barriers (Access to care)

- Finding age appropriate, quality and approachable health care providers
- Paying for health care
  - ➤ Insurance
  - ➤ Availability of public assistance programs

Structural barriers (External factors related to care)

- Transportation
- Employment
- Living independently (the ultimate goal)

Overcoming the Barriers: How and When Do I Support My Child Through Health Care Transition?

What you need to know in order to successfully support your youth during the transition process

Teachable moments

- It's never too early to start talking about independence and the transition to adulthood
- Recognize opportunities to talk about transition issues
- Model behavior, advocacy, and skills they will need as an adult
- Ask your youth what they want you to do - do not just assume

Assess your situation (the variables)

- Age of youth, age appropriateness of tasks and skills
- Abilities (cognitive, physical, emotional) of youth
- Remember, he or she is a teenager, help them understand their priorities
- Determine how much time you have to plan
- Discuss how your culture/beliefs affect the healthcare your family receives
- Availability of family support; get help from other family members to develop a plan
- Find out if your youth's physician is willing to do a formal transition plan

Work with others to help youth in health care transition

- Schools, counselors, school nurses, Individualized Education Plan (IEP) team
- Pediatricians and pediatric specialists
- Dietician/nutritionist
- Coaches or health teachers
- Other parents and other youth

Other Ways I Support My Child Through Health Care Transition

Make sure your child knows

- About her or his condition or disability
- Symptoms of concern
- How to determine an emergency
- Who to call in case of an emergency

- How to schedule his or her own appointments
- How to arrange for her or his own transportation
- How to keep track of and order his or her own medication refills
- To write down questions before she or he visits the doctor
- To speak up and ask questions (advocacy)
- That he or she can talk to the healthcare provider about difficult subjects that may be hard to discuss with family in the room, like relationships, sex, and birth control
- To ask for an explanation of medical tests and reports
- To carry her or his insurance card and portable medical summary
- How to order and take care of medical equipment and assistive technology

Ages and Stages of Transition

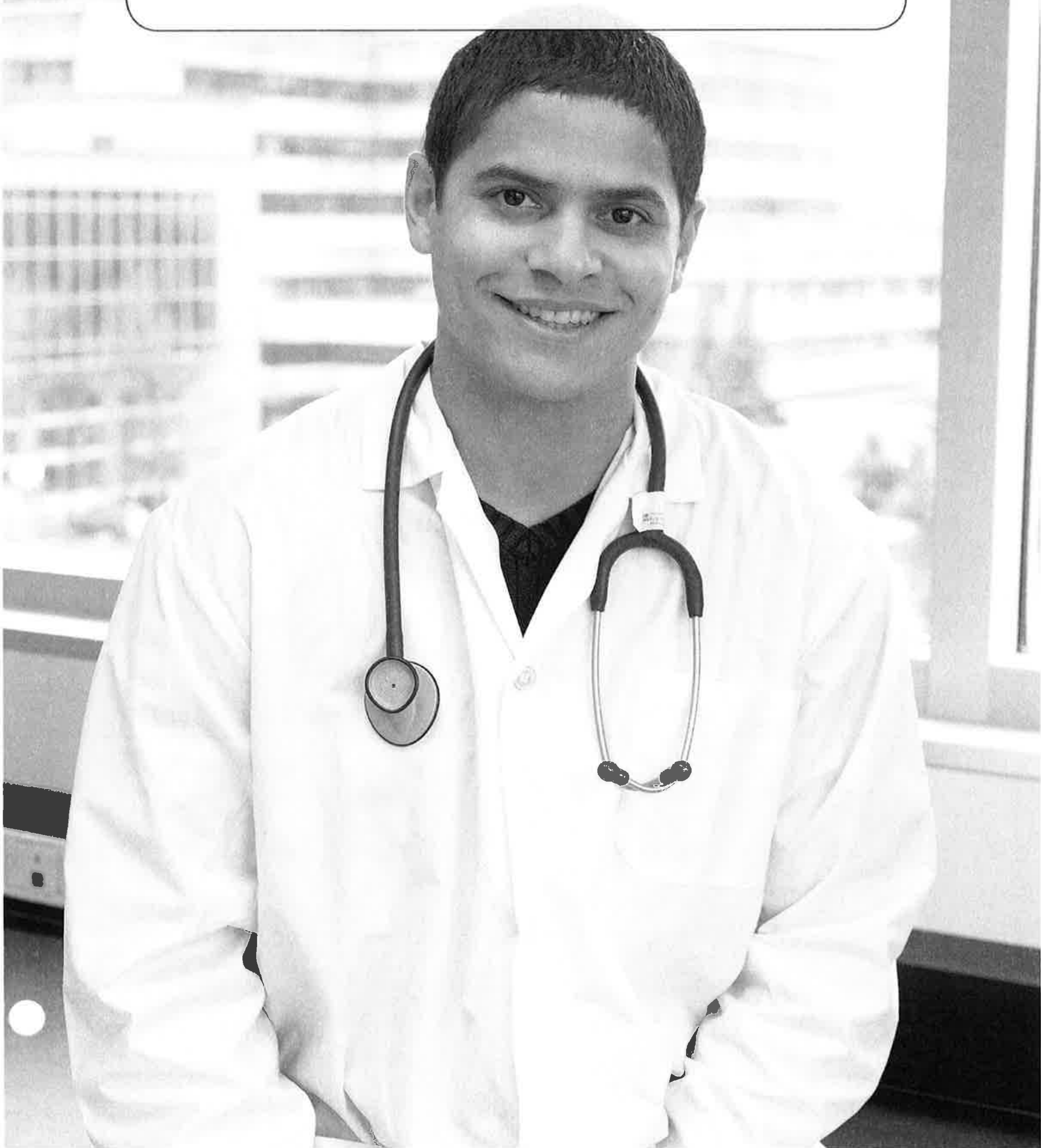
Check the Toolkit for Checklists and Timelines for Healthcare Transition!

Many checklists, questionnaires, and profiles are available to help determine your youth's transition needs. This is an excellent opportunity for you to discuss knowledge and skills and assess your youth's readiness to participate in the health care transition process. Some of the checklists may include age-specific guidelines, but please remember these are recommendations only, not hard and fast rules! We've included several check sheets for your review.

Generally, discussion of health care transition should begin **early** in adolescence. It is important to remember that it is never too early and never too late to begin the process. The actual transfer of care occurs when everyone feels it is time. The pediatric physician, parents, youth and adult healthcare provider should all be in agreement about when the actual transfer of care should occur.

Chapter 2

Medical Home and Health Care Transition



Chapter 2 What is a Medical Home?

Medical Home – Definition

A medical home is not a building, house, or hospital but an approach to providing health care services in a high-quality manner.

The medical home concept is the framework for establishing parents and youth as equal partners with medical providers.

One of the objectives of a medical home is to support health care transition for youth and young adults. This makes your medical home a logical first step for a discussion about transition.

The American Academy of Pediatrics (AAP) defines a medical home as, "an approach (idea) to providing health care services in a high-quality (good), comprehensive (complete) and cost-effective manner."[2]

The AAP definition of medical home can be broken down into specific categories that are related to the quality of primary care. A medical home describes primary care that is:

Accessible

- Care is provided in the child's community
- All insurance, including Medicaid, is accepted and changes are accommodated
- Families or youth are able to speak directly to their medical home provider when needed

Family-Centered

- Mutual responsibility and trust exists between the patient and family and the medical home
- The family is recognized as the principal caregiver and center of strength and support for the child
- Clear, unbiased, and complete information and options are shared on an ongoing basis with the family

Continuous (relates specifically to health care transition)

- Same primary pediatric health care professionals are available from infancy through adolescence and young adulthood
- Assistance with transitions (to school, home, adult services) is provided
- The medical home provider participates to the fullest extent allowed in care and discharge planning when the child is hospitalized or care is provided at another facility or by another provider

Comprehensive

- Health care is available 24-hours-a-day, 7-days-a-week
- Preventive, primary and tertiary care needs are addressed
- The medical home provider advocates for the child, youth, and family in obtaining comprehensive care, and shares responsibility for the care that is provided

Coordinated

- A plan of care is developed by the physician, child or youth, and family and is shared with other providers, agencies, and organizations involved with the care of the patient
- A central record or database containing all pertinent medical information, including hospitalizations and specialty care, is maintained at the practice. The record is accessible, but confidentiality is preserved

Compassionate

- Concern for well-being of child and family is expressed and demonstrated in verbal and nonverbal interactions
- Efforts are made to understand and empathize with the feelings and perspectives of the family as well as the child or youth

Culturally Effective

- All efforts are made to ensure that the child or youth and family understand the results of the medical encounter and the care plan, including the provision of professional or paraprofessional translators or interpreters, as needed
- Written materials are provided in the family's primary language

Check the Toolkit for the Medical Home Index Tool!
You can use the Medical Home Family Index to help understand how a medical home can help make your child's health care better. Take a few minutes to complete the index and use it to evaluate your child's current health care provider.

Health Care Transition and the Patient Centered Medical Home

As your youth becomes a young adult and moves from a pediatric medical home into the adult health care systems, the characteristics of medical home are more focused on patient centered care. Below are some characteristics of the patient centered medical home that are important to remember as he or she begins the process of health care transition. These elements of medical home are more focused on the principles of coordinated care, which includes:[3]

A **plan of care** is developed by the physician, practice care coordinator, youth, and family in collaboration with other providers, agencies, and organizations involved with the care of the patient.

A **central record or database** containing all pertinent medical information, including hospitalizations and specialty care, is maintained at the practice. The record is accessible, but confidentiality is preserved.

The **medical home physician shares information** among the youth, family and consultant, and provides a specific reason for referral to appropriate pediatric sub-specialists, surgical specialists, and mental health/developmental professionals.

Linkages to support groups and other **community-based** resources.

The medical home **physician assists the young adult in understanding clinical issues** when he or she is referred for a consultation or additional care.

The medical home **physician evaluates and interprets the consultant's recommendations** for the patient and, in consultation with them and the sub specialists, implements recommendations that are indicated and appropriate.

The **plan of care is coordinated** with educational and other community organizations to ensure that the special health needs of the patient are addressed.