Health Care Transition

A Youth Guide to Transition from Pediatric to Adult Health Care

Carolina Health and Transition (CHAT)*

A Youth Guide to Transition from Pediatric to Adult Health Care

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Introduction

Carolina Health and Transition Project (CHAT)

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 is designed to serve as a guide for young adults with special health care needs, who are preparing to transition from pediatric to adult health care. By using this handbook and toolkit, YSHCN should be able to:

Define:

- Health care transition
- Self advocacy
- Roles of a Primary Care Provider (PCP)
- In Case of Emergency (ICE)

Learn about:

- Carolina Health and Transition (CHAT)
- A medical home and who is involved
- Information and statistics
- How to talk to your doctor
- Goals of a healthy life

Understand:

- What health and transition have to do with me
- The differences between child health care and adult health care
- The parts of a successful transition
- How to use the toolkit

Case Study

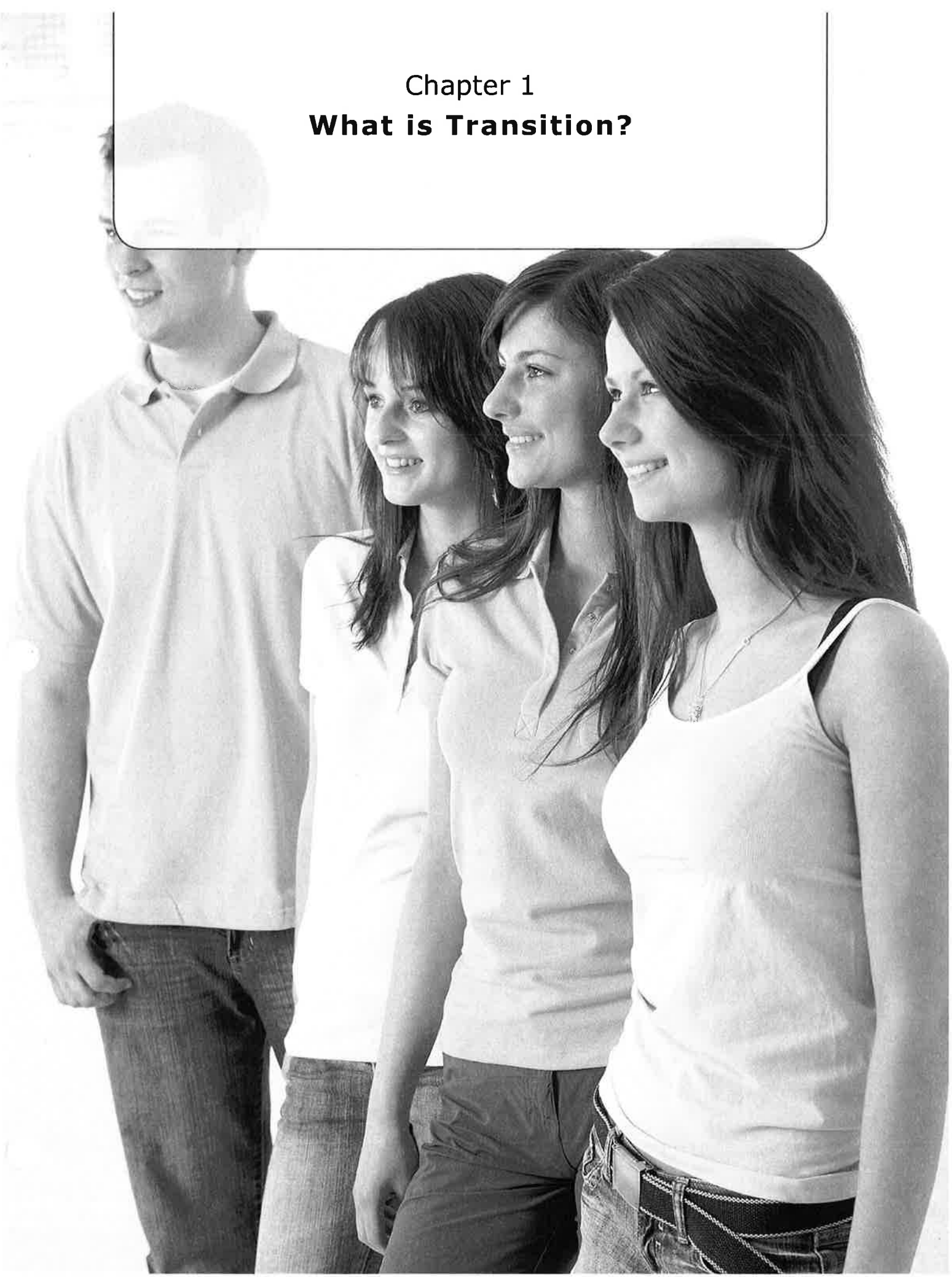
Each chapter also contains a case study that accompanies the DVD that is included with the manual. Each case study relates to a scenario on the DVD. They can be used to help you see how other youth address a different part of the transition process.

Toolkit

The toolkit included in the back of this handbook is designed to provide you with several resources that can help support your health care transition process. You can use these tools and create your own notebook, or remove them and take them with you when you go to visit your doctor.

Chapter 1

What is 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 planned movement from pediatric to adult health care systems, with a primary focus on youth with special health care needs.

The Maternal and Child Health Bureau of the U.S. Department of Health and Human Services defines children and youth with special health care needs (YSHCN) as: ***"those who have or are at risk for chronic physical, developmental, behavioral, or emotional conditions who require health and related services of a type or amount beyond that required by children and youth generally"***[1].

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[2]

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 ultimately lead to positive health outcomes.

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

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
3) structural

Potential Barriers to Health Care Transition

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)

Ages and Stages of Transition

Many checklists, questionnaires, and profiles are available to help you determine your transition needs. This is an excellent opportunity for you to apply your knowledge and skills, as well as assess your 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 checklists in the toolkit as examples.

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. Your pediatric doctor, parents, adult healthcare provider, and YOU should all be in agreement about when the actual transfer of care should occur.

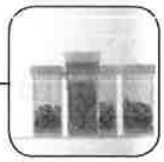
Parts of a Successful Transition[3]

- Start early
- Self-determination
- Person-centered planning
- Steps to get ready for adult health care
- Work/Independence
- Getting ready for college
- Inclusion in community life
- Learning the rules of adulthood

Taking steps to move toward adult health care[4]:

1. Start early - Plan ahead!
2. Know how to explain your health care needs.
   Make a list of all the things you need to keep yourself healthy.
3. Keep a record of your appointments, important medical history, phone numbers of doctors and your medications.
4. Begin to make your own medical appointments.
5. Write down questions for your doctor or nurse practitioner before your visit.
6. Spend time alone with your doctor or nurse practitioner to discuss your health concerns.
7. Learn about your health insurance and health care finances.
8. Talk to your pediatric doctor or nurse practitioner about when is a good time for you to transfer your care.
9. See your primary care provider on a regular basis to help you stay healthy.
10. Meet adult providers before you begin your transitions.

Be strong! Ask questions! Be part of the plan!



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

Rules of Adulthood

The following are rights and responsibilities that come at a certain age. These relate to everyone whether you have a disability or not:

RESPONSIBILITIES/RIGHTS	AGE
Vote	18 years or will be on election day
Get married	**Emancipated** (16 years and older)
Make a **will/ living will**	18 years or older unless emancipated
Make a contract*	18 years or older unless emancipated
Being tried in adult criminal court	Begins at age 16
Self-support	18 years or older unless emancipated
Jury Duty if called	18 years or older unless emancipated
Liable for contracts	18 years or older unless emancipated
Registering for the Draft	It does not matter if someone is capable of serving or not. EVERY male citizen and alien residing in the US must register within 30 days of his 18th birthday. Failure to register for the draft is a federal crime.

*You have to sign a contract when you rent an apartment, buy a car, or take out a loan

Youth should understand that their parents do not continue to have decision-making authority once you turn 18 years old. Young adults with and without disabilities are expected able to act on their own behalf unless a court of law decides otherwise.

There are many choices for individuals who need assistance with decision making. Some choices include full guardianship, partial guardianship, representative payee, case management and other supports, Healthcare Power of Attorney, etc.

These terms are described in Chapter 5 in the section on **Insurance Options and Terms**.

Person-Centered Planning

Person-centered planning is a process oriented approach to empowering youth, particularly those with developmental disabilities, and other chronic health conditions. It is a way to identify your goals and measure progress toward your desired outcomes in the future.

A core function of the transition process is the development of a health care transition plan, and includes a series of discussions or interactions among you, your family, health care provider, care coordinator, and others. This group of people is called a ***planning team***.

The main purpose of the person-centered plan is to provide Information to you and your family in a way everyone understands. It will also help your decision-making and increase your ability to set goals and make them happen.

Self-Determination

"Self-Determination is making my dreams happen by having choices and control over my life!"

- Full Life Ahead (2006)

The Self-Determination Learning Model includes skills that help prepare you as you make the transition to adulthood by encouraging you to:

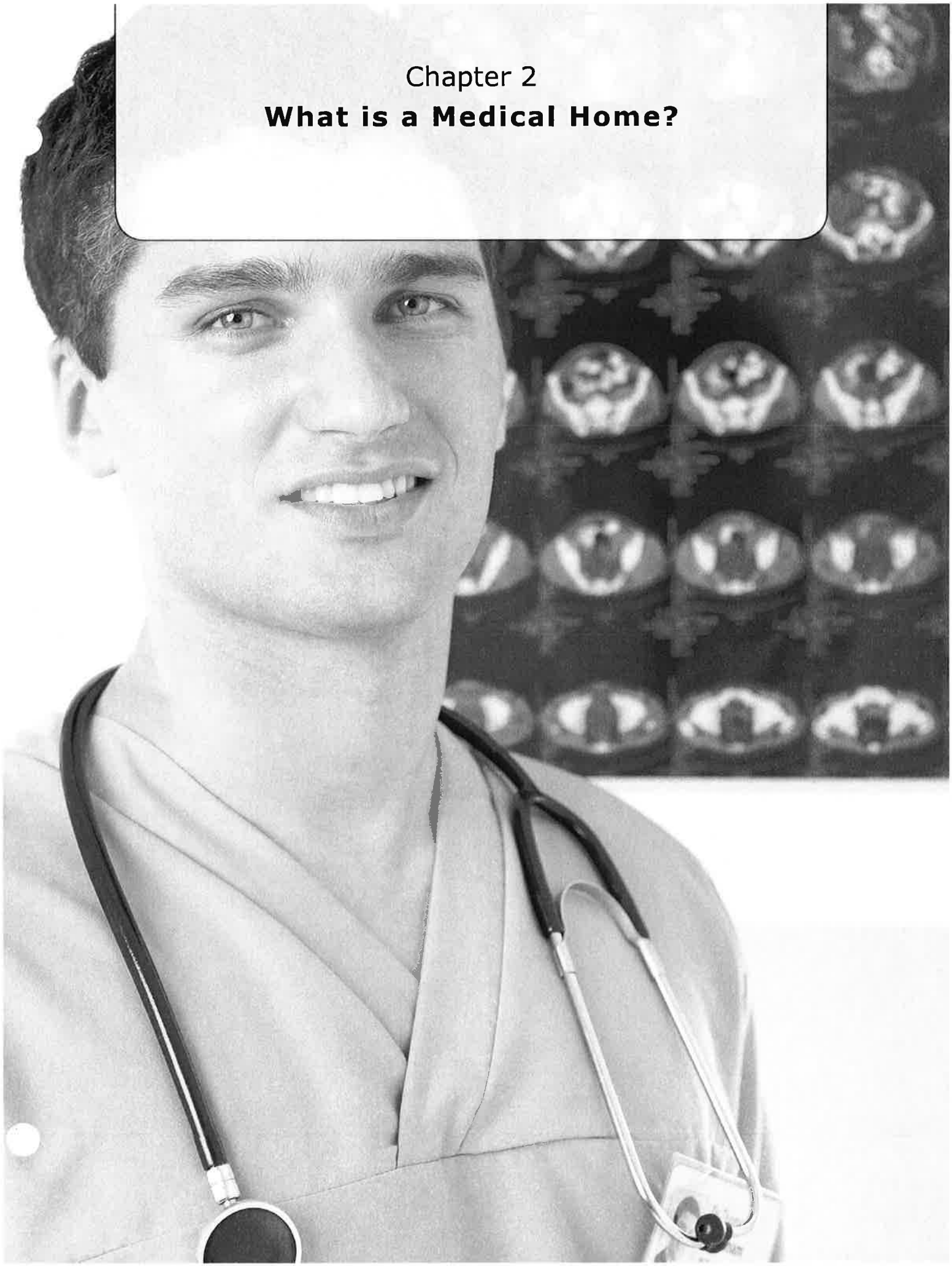
1. Set goals
2. Take action
3. Adjust the goal or plan

By working with this model, you learn to become problem solvers, set your own transition goals, take action on those goals, and evaluate your achievement. You can also learn to adjust your goals or plans as needed. These skills will help you to have a better quality of life as you become more empowered to make your own decisions and advocate for your health care needs.

Case Study

Meet Lee, Marcel, Chris, RJ, and Sam. These five young adults are currently working to transition from pediatric to adult healthcare.

Each individual is at a different stage of transition. As you read through the manual and watch the DVD, take time to compare your own experiences with the experiences of these five individuals.



Chapter 2

What is a Medical Home?

Chapter 2 What is a Medical Home?

Medical Home – Definition (Pediatric)

A pediatric 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 their pediatric medical providers. It is important to understand how the medical home concept works with your pediatrician and how that may be slightly different as you become an adult.

One of the objectives of a medical home is to support the health care transition process 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."

The AAP definition of medical home[5] can be broken down into specific categories that are related to the quality of primary care. A medical home describes pediatric 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 youth.
- Clear, unbiased, and complete information and options are shared on an ongoing basis with the family.

Continuous (relates specifically to health care transition)

- Some primary pediatric health care professionals are available from infancy through adolescence and young adulthood – such as family physicians.
- Assistance with transitions (to school, home, adult health 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 the 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.

Key Players in Medical Homes

The key people in a medical home (and transition planning team) include, but are not limited to:

- Primary care doctors
- Specialty health care providers
- Family
- **You**

These key players are significant as part of a medical home, because they also become part of your health care transition team. Others that may play an important role in your transition planning team include, but are not limited to:

- Care coordinator
- School nurse
- Community services staff
- Nutritionists
- Pharmacist
- Mental/behavioral health professionals
- Dentists

Having a medical home is very important as you begin the process of transition. Each of the members of your medical home/transition team can provide valuable information as you are planning for your movement into the adult health care system.

Health Care Transition and the Patient Centered Medical Home

As you become a young adult and move 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 you begin the process of health care transition. These elements of medical home are more focused on the principles of coordinated care, which includes[6]:

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

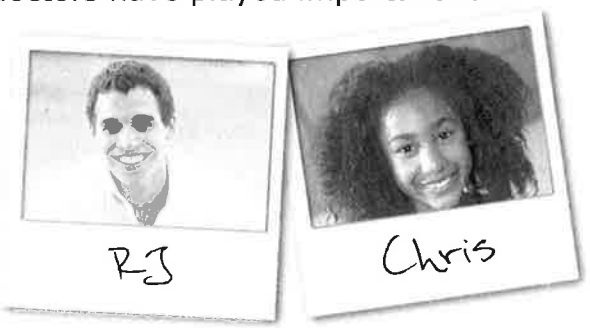
The medical home **physician evaluates and interprets the consultant's recommendations** for the patient and, in consultation with them and the sub-specialists, implements recommendations that are indicated and appropriate

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

Case Study

Each of these five young adults understands the concept of a pediatric and patient-centered medical home.

- RJ and Chris feel that their pediatric doctors have played important roles in their medical homes.



- Marcel believes that his family is just as important as his doctors in his medical home.

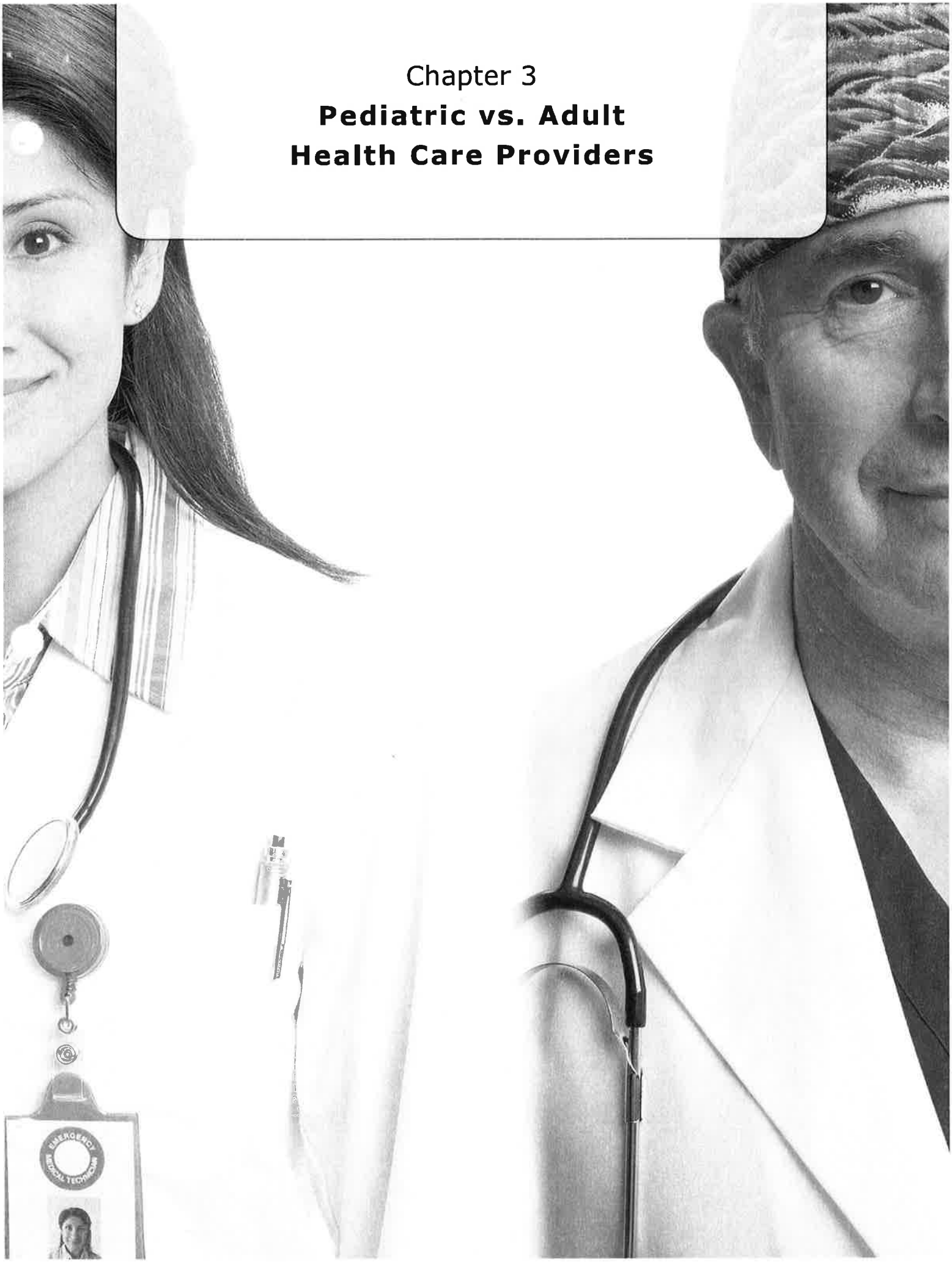
- Sam thinks that specialists and her pharmacist are a very important addition to her medical home because when they work together she can get the best medical care.

- Lee feels that she is the most important part of her medical home.

All of these people are important to the medical home. The key players in a medical home will differ for each person, particularly as you begin to work with adult health care providers.

Chapter 3

Pediatric vs. Adult Health Care Providers



Chapter 3 Pediatric vs. Adult Health Care Providers

Roles and Responsibilities of Health Care Providers

The pediatric provider is involved in educating you about lifelong transition skills such as proactive planning, problem solving, self-advocacy, and negotiation. These skills are not only important in the process of becoming an adult, but also for learning how to gain access to services from adult health care providers.

There are many differences in pediatric health care vs. adult health care. These differences are important to remember during the transition process.

Examples of these differences include:

PEDIATRIC HEALTH CARE	ADULT HEALTH CARE
One doctor provides almost all medical care	Different doctors for different health needs
Informal and relaxed	Business-like, more formal setting
Warm, optimistic	Rigorous exams for health problems
Scheduling is more flexible	Advance planning for appointments required
Family management of health needs	Patient self-management
Family centered	Patient centered

Collaboration Between Youth, Families and Health Care Providers

One of the most important keys to successful collaboration between youth, families, and health care providers is **communication**.

There are also ways that you can effectively communicate with your health care providers so you can receive the best care possible. We have included a transition health care assessment that can be used to help you identify your health care issues and support the communication process.

Communicating with health care providers and care coordinators

One of the best sources for support and ongoing education is your primary care providers – both the pediatrician and adult/family physicians.

Their role in the health care transition process should include:

- Provision of preventative care and teaching healthy lifestyle choices
- Identification and treatment of common medical conditions
- Assessing the importance of medical problems and giving proper direction for that care
- Providing information on insurance options as an adult
- Collaborating with a care coordinator to support the transition process

Role of Care Coordinators[7]

Care coordination plays an important role to improve communication between the patient and doctor, and is a key part of the patient centered medical home. Below are some of the ways that care coordinators can help support you and your family to get connected to appropriate services and resources in a coordinated effort to achieve good health.

1. **Assess and Identify Need** – Activities preformed by a care coordinator are based upon a comprehensive assessment that can sometimes include a psychosocial assessment of the youth and family. Identifying needs is the first step in the care coordination process. The development and use of an assessment tool will help in gathering the information needed to develop a transition plan of care.

2. **Develop a Plan of Care** – After identifying the needs, a plan of care is developed with the youth and family where goals and outcomes are discussed. The care coordinator may clarify with the youth which action steps he or she will address and which will be addressed by the care coordinator.

3. **Put the plan into action** – Following the plan, the care coordinator can help the youth take actions to work towards the desired outcomes. Identified service providers and programs all work towards fulfilling the needs of the youth. The care coordinator organizes the process and helps the youth and family with resources, referrals, and coordinating care with specialty physicians, schools and other agencies. They can also provide assistance with identifying and communicating with an adult care provider.

4. **Evaluate** – Periodic evaluations are performed to reassess the plan of care and to address new needs.

Ask your provider if there is a care coordinator on staff. If there is not, find out if there is someone available who could fill that role in their office.

Case Study

Lee is a sixteen-year-old student who also works a part-time job in the afternoon. Lee has recently been working on transitioning from pediatric to adult healthcare. Lee feels comfortable going to the doctor's office by herself, but continues to struggle with communicating with the doctors and nurses.

Sometimes Lee can be shy when talking to her doctor and she can also be vague when answering her doctor's questions. Lee succeeds at scheduling her doctor appointments so that they do not interfere with school or work. Lee will continue to work towards her goal of transitioning to adult health care.

Lee