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

Sponsored by:

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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

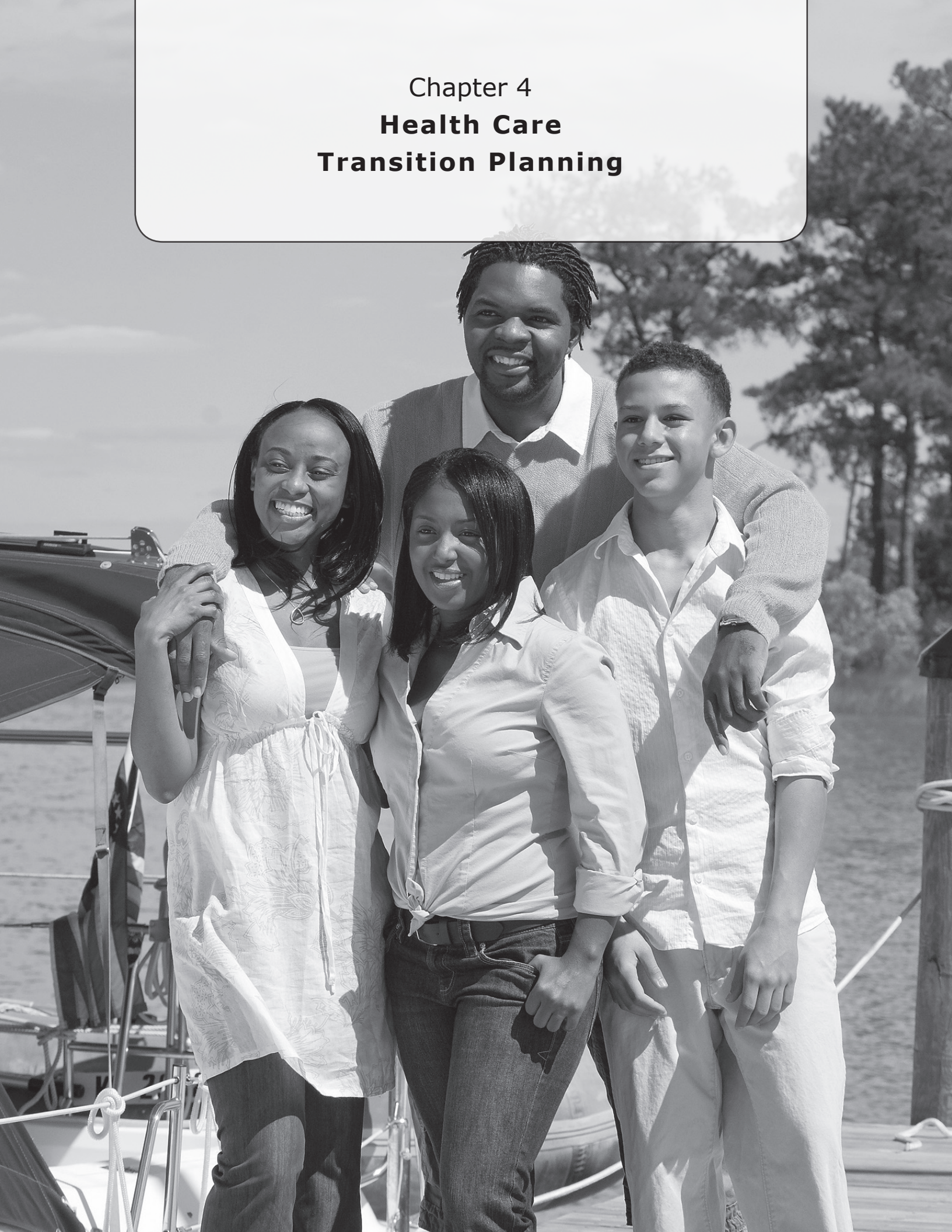
Lee is a sixteen-year-old student who also works a part-time job in the afternoon. Lee has recently been working on transitioning from pediatric to adult healthcare. Lee feels comfortable going to the doctor's office by herself, but continues to struggle with communicating with the doctors and nurses.

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

Chapter 4

Health Care Transition Planning



Health Care Transition Plans

A **health care transition plan** is different from a regular care plan, because the goals and objectives are specifically about how to address your health and medical needs as you enter adulthood.

Transition planning should at a minimum include the pediatric provider, the youth, the family, the care coordinator and, if appropriate, an adult health care provider. This plan should be written with specific goals and tasks for each member of the group.

Some topics to consider include:

- Health condition management
- Health promotion/proactive wellness
- Increasing responsibility
- Health care funding options (e.g. insurance)
- Functional independence
- High school goals/plans
- Post-secondary school plans
- Work plans
- Independent living issues
- Community inclusion
- Actual transfer of care

It is important to realize that you provide **valuable input** during the creation and maintenance of this document.

Be sure to review and update the plan each year, or more frequently, in case there are changes in needs, concerns, and/or priorities.

A sample transition care plan is included on the next page. But you can create your own or download another from **www.hrtw.org**. There are also blank copies of transition care plans included in the toolkit of your handbook.

How to manage your health care

The most important part of understanding the transition process is to master the ability to manage your own healthcare through:

- 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 you are now 18 years old)
- Knowledge of YOUR health condition
- Knowledge of insurance options
- How to handle medical emergencies

The worksheets included in the back are designed to help you plan for the transition process, as well as guide you through the steps listed above.

Record keeping

While working with your health care provider or pediatrician, it is important to keep records of your visits and conditions that are being treated. By keeping a record of your important medical treatments, you can provide your health care provider with enough information to help them facilitate your transition to the adult health care provider at the appropriate time. It will support your success in the health care system as an adult.

Here are two ways to keep medical documentation and health records:

- Have a complete, current record of health care coordination (care notebook)
- Use a portable medical summary

Care Notebook

- Contains information about all doctors and specialists that provided health and medical care
- Includes medical history, disability information, past records (keep at home)
- Should be complete and current
- Keep multiple copies (in case something happens to the original copy)

Portable Medical Summary

One of the most important documents to help you plan the transition process is the **portable medical summary**. The portable medical summary is a worksheet that you can keep with you and provides an overview of your medical condition – similar to a short medical biography.

It includes:

- Current and important medical information you want others to know (physician appointments)
- One-page medical summary to carry with you, in case of emergency

A sample of a completed **portable medical summary** is shown on the next page and a blank one for you to complete is included in the ***Toolkit***. An electronic version can also be downloaded at **www.hrtw.org** so you can change it to fit your needs.

Take this opportunity to work together with your parent on each of the methods of record-keeping. This will improve your knowledge about your history and condition, and will also prepare you to become responsible for your own health information.

Once you choose a portable medical summary form that works for you, take it to your doctor so he or she can help you fill it out.

Then be sure to keep it with you at all times!

More resources to help you find out information that should be included in your health records:

- Information you and your family already have at home
- Internet based health resource websites
- Peer support (friends or support groups)
- School-based health center or school nurse
- Local support agencies

Portable Medical Summary – Sample

LEGAL NAME
Address, City, State, Zip
Phone, cell, email

INSURANCE	Company Name	Certificate # ADD		BC Plan ADD / BS Plan ADD Rx BIN ADD	
		Group # ADD		ADD PH / 800-XXX-XXXX	
Legal Health POA *	ADD Name	Relationship	Cell ADD	Work ADD	Work ADD
	ADD Name	Relationship	Cell ADD	Work ADD	Work ADD
	ADD Name	Relationship	Cell ADD	Work ADD	Work ADD

DOB xx-xx-19xx HEIGHT/WEIGHT: x'x", xxx lbs ADVANCE DIRECTIVES: YES NO DNR: YES NO
SS# xxx-xx-xxxx BLOOD TYPE: X positive/negative ORGAN DONOR: YES NO

ADD comment about pain threshold
ADD comment regarding patient preference
ADD comment regarding patient preference.

ALLERGY: ADD

HEALTH ISSUES			
ADD Body system	ICD-9 XXX	ADD Name of Health Issue	age on onset
ADD Body system	ICD-9 XXX	ADD Name of Health Issue	age on onset

MEDICATIONS		
Rx	What for?	Name of Drug Dosage x ? how many times a day, ADD RX #
OTC		List any over the counter Drug –indicate daily or PRN

MEDICAL HISTORY					
Add Body System	ICD9 - XXX	Diagnosis?	age on onset	age next episode	age next episode
	ICD9 – XXX	Diagnosis?	age on onset	age next episode	age on onset
	ICD9 - XXX	Diagnosis?	age on onset	age next episode	age on onset

MEDICAL HISTORY					
	SURGERIES				
	ICD9 - XXX	What treatment? Note if benign or cancer	age on onset	age next episode	age on onset
	ICD9 - XXX	What treatment? Note if benign or cancer	age on onset		
Add Body System	ICD9 - XXX	Diagnosis?	age on onset	age next episode	
OTHER		Diagnosis?	age on onset	age next episode	
			age on onset	age next episode	

MEDICAL TESTS			
Blood	Month/Year	Fasting	Cholesterol XXX, HDL XX, LDL XX, Trig XXX, CRP XX, glucose XX
	Month/Year	Negative	- Name of Company, Address
	Month/Year	Normal	- Name of Company, Address

IMMUNIZATIONS					
Tentanus YR	TB YR	Pneumococcal vaccine YR			

FAMILY HISTORY		
Father	Alive/Deceased Age?	Health Issues, Cause of Death
Mother	Alive/Deceased Age?	Health Issues, Cause of Death
Child	Alive/Deceased Age?	Health Issues, Cause of Death

PHYSICIANS		
FAMILY PRACTICE	Name	Phone Address
Name	Name	Phone Address

OTHER		
Dental	Name	Phone Address
Rx – Pharmacy	Name	Phone Address

What do health and transition have to do with it? EVERYTHING!!

Successful health care transition can lead to:

- Better overall health
- More productive life
- Self-sufficiency and independence
- Prevention of secondary conditions
- A smooth transfer to an adult primary care provider

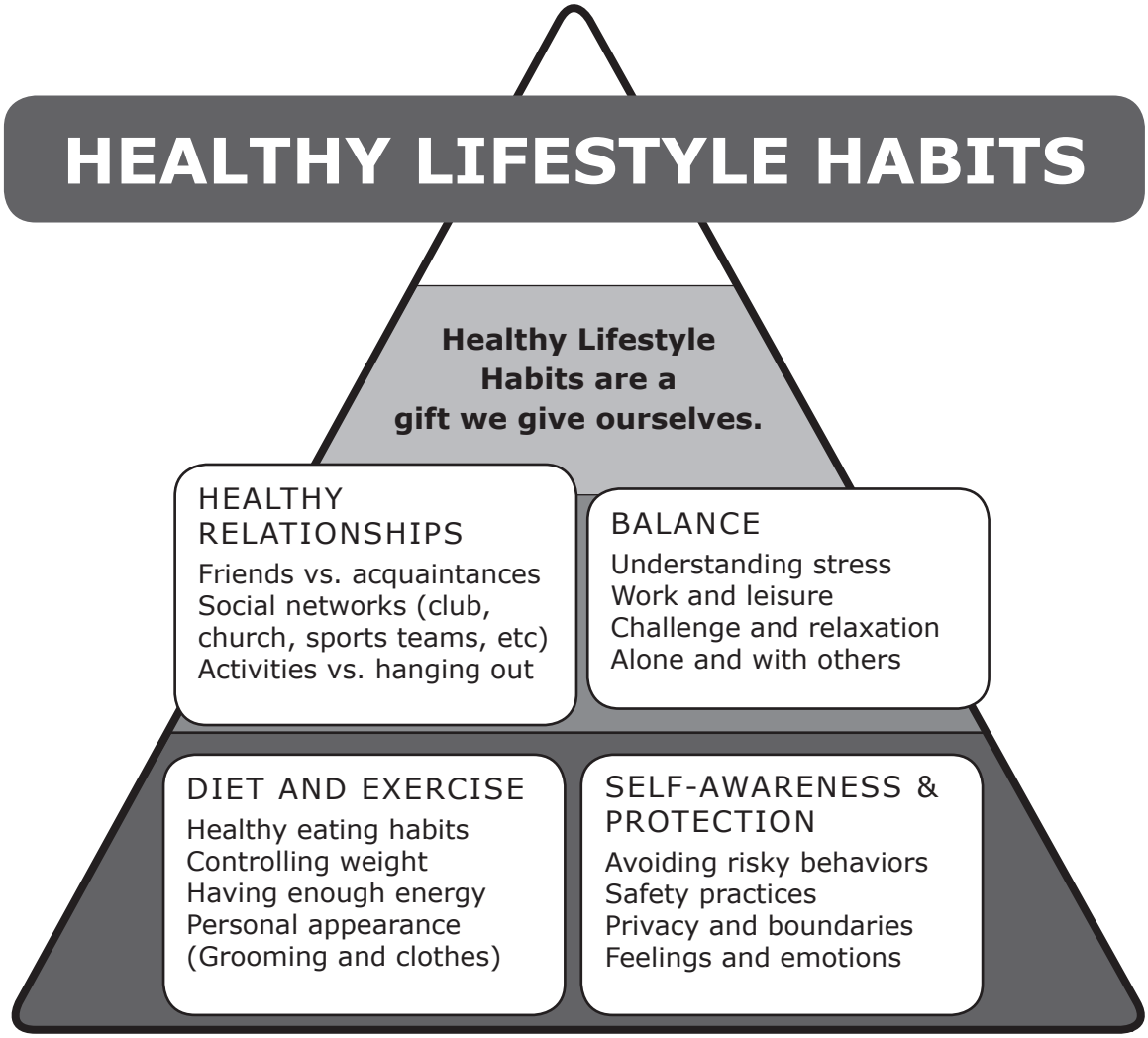
Having good health would mean:

- Better time management
- Developing healthy lifestyle habits (see healthy lifestyle habits pyramid)
- More time to spend with friends
- Fewer trips to doctor
- Fewer money/insurance problems
- Ability to choose your own doctor
- Better self-awareness

<u>NOT</u> having good health can mean:

- Development of secondary conditions/complications
- Dealing with sudden medical problems and spending more time with doctors instead of enjoying life to the fullest
- Missed school/job opportunities
- No time for friends/loss of friendships, supports, and resources
- More money/insurance problems

The key to developing better lifestyle habits



General Screenings and Immunizations for Women

HEALTH CATEGORY	SCREENING TESTS	AGES 18-39
General	Complete checkup	Discuss with doctor or nurse
	Thyroid test	Start at 35, then every 5 yrs
Heart	**Blood pressure** test	At least every 2 years
Heart	**Cholesterol** test	Start at age 20, **TBD**
Diabetes	**Blood glucose/blood sugar** test	Discuss with doctor or nurse
Reproductive	Pap test and pelvic exam	Every 1-3 years if you have been sexually active or older than 21
Reproductive	**Chlamydia** test	Yearly until age 25 if sexually active. Older than age 25, get this if you have new or multiple partners. All pregnant women should have this test
Reproductive	**STD**s	Before initiating **sexual intercourse**
	Mental Health Screening	Discuss with doctor or nurse
Eye and Ear	Eye exam	Visual problems: 1 (20-29); 2 exams (30-39)
Eye and Ear	Hearing test	Starting at age 18, then every 10 years
Oral	Dental exam	1 or 2 times a year
Immunizations*	Influenza vaccine	TBD
Immunizations	Tetanus-Diphteria booster vaccine	Every 10 years
Immunizations	Human Papillomavirus vaccine (HPV)	TBD
Immunizations	Meningococcal vaccine	TBD if college
Skin	Mole exam	Monthly mole self-exam; by a doctor every 3 years, starting at age 20

* Some immunizations may be covered by your insurance up to a certain age

General Screenings and Immunizations for Men

HEALTH CATEGORY	SCREENING TESTS	AGES 18-39
General	Complete checkup	Discuss with doctor or nurse
Heart	Blood pressure test	At least every 2 years
Heart	Cholesterol test	Start at age 20, TBD
Diabetes	Blood sugar test	Discuss with doctor or nurse
Reproductive	Testicular exam	Monthly self-exam; and part of a complete checkup
Reproductive	Chlamydia test	TBD
Reproductive	STDs	Before initiating sexual intercourse
	Mental Health Screening	Discuss with doctor or nurse
Colorectal	**Rectal exam**	TBD
Eye and Ear	Eye exam	Visual problems: 1 exam (20-29); 2 exams (30-39)
Eye and Ear	Hearing test	Starting at age 18, then every 10 years
Oral	Dental exam	1 or 2 times a year
Immunizations	Influenza vaccine	TBD
Immunizations	Tetanus-Diphteria booster vaccine	Every 10 years

Case Study

Marcel is a 19-year-old man who has recently begun to transition from pediatric to adult healthcare. Marcel communicates through sign language, but his doctor does not. Marcel understands that communication is important; therefore, he has been focusing on completing his portable medical summary. The portable medical summary should have the information that the doctor will need, including any medications that Marcel is currently taking, health issues, personal and family medical history, and immunizations. Marcel has bridged the communication gap with his doctor by having all of this information written down. Marcel also writes down his symptoms in detail on the "Illness visit" sheet so his doctor will understand exactly how he is feeling.

Marcel believes that his goal of transitioning can be achieved by using the resources available in the CHAT manual.

Sam is a 26-year-old woman who lives alone in an apartment. Sam makes most of her healthcare decisions independently but sometimes needs assistance to remember how

to schedule an appointment or refill her prescriptions. Sam and her family feel that it is important for her to have resources available that will remind her how to do these things. Within the Transition Toolkit Sam finds worksheets that may assist her when she is scheduling a doctor appointment or calling the pharmacy to get her medicine refilled.

Additional Tips for Transition Planning:

- Have a plan for review and revision of the original document.
- Decide if the plan should be reviewed annually or only if there is a change in your condition.
- Periodically check in with the provider to evaluate progress.
- Make sure everyone is on task.
- Determine if there have been any unexpected outcomes or changes.
- Be sure to include everyone should there be any revisions.

Chapter 5

Health Care Coverage and Transition

Chapter 5 Health Care Coverage and Transition

Health Care Coverage for Adults with Disabilities

In many states, the eligibility requirements for health insurance change as soon as you become 18 years old. As a result many young adults are unable to maintain adequate health care coverage. In fact, lack of adequate insurance is the main reason young adults with disabilities are not able to manage their own health needs.

Each state has different rules and regulations that determine age limits, parental continuation of coverage, dependency, and eligibility requirements. It is important to check the laws that govern these policies and determine which options that may be possible for you, based on your health condition and medical needs.

Best advice: Start early and plan ahead!

Ask your parents to help you so you can make good decisions. You should do this before you turn age 18.

- Some insurance policies allow young adults to continue coverage, if you are a full-time student. Some insurance policies have other rules.
- Some policies will allow some continued coverage up to age 21 or 25.
- Some will allow continued coverage forever for young adults if they are disabled (according to the Social Security Administration's definition) and if the parent continues to provide 50% or more of their financial support (money).

This must be considered carefully if you plan to apply for Supplemental Security Income (SSI). Some rules of SSI payments are based on whether the young adult is no longer being claimed as a dependent by the parents. Others will allow the parents to continue to support their child at a higher payment level.

Insurance Options and Terms

COBRA

A young adult who no longer qualifies for continued coverage under their parent's insurance plan can continue to get coverage for a period of time under a current insurance plan by paying the individual premiums.

This is known as **COBRA** coverage–**an insurance plan that covers you in between two long-term insurance plans. A young adult can be covered under COBRA for up to 36 months after leaving the parent's health insurance plan.**

COBRA must be put in place at the time coverage is scheduled to end and can be quite costly, but it may prevent the 63-day lapse in coverage that might disqualify future insurance coverage due to a **"pre-existing condition"**.

Even though the monthly COBRA premiums may cost a lot of money, it may be a good short-term solution. If the health and dental plans are separate, each should be considered (thought about) based on its own cost and possible value.

High Risk Insurance Pool

If you are unable to receive health insurance through a private provider because of your medical conditions, there is another way to obtain some health coverage in NC. The high risk insurance pool is offered as a way to provide insurance for medical purposes, particularly when no other insurance is available. Some of the ways you can be eligible for this insurance coverage are if:

- You are a North Carolina resident and legal resident of the United States;
- Do not have access to health care coverage under an employee plan or as a dependent of an employee
- Don't quality for Medicaid, Medicare or SCHIP
- Have a diagnosed condition (see list of pre-existing conditions)

The benefits include but are not limited to: well and illness visits, medicines, vision and hearing care, dental care, medical equipment and supplies, lab tests, counseling, immunizations, hospital care, therapies, and surgery.

For additional information, please contact **www.inclusivehealth.org**.

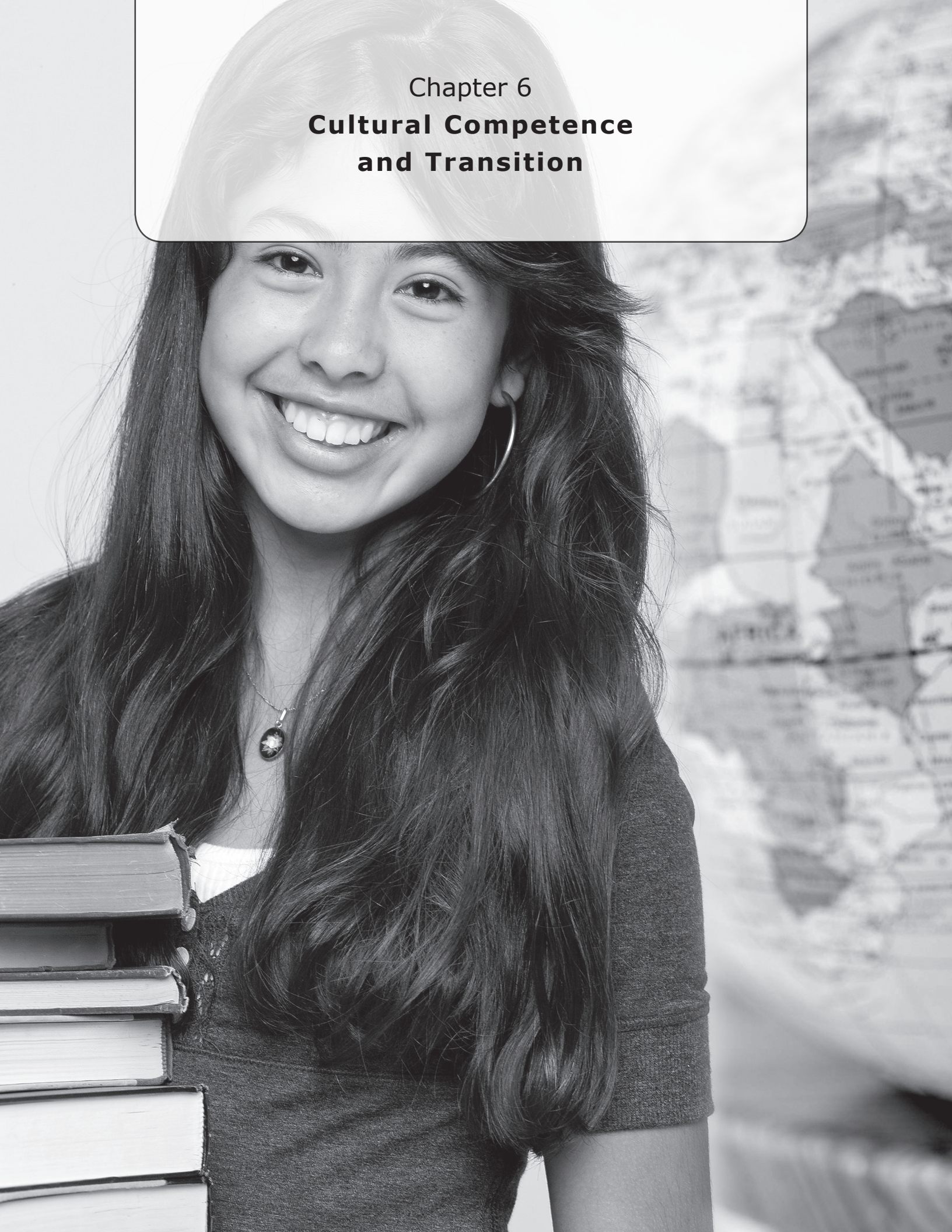
Legal issues related to health care coverage

Medical Power of Attorney

A Medical Power of Attorney is a document, signed by a competent adult; designating a person that she/he trusts to make health care decisions on their behalf should they become unable to make such decisions. We have provided a sample document in the Appendix for your review. Check the following websites for more information: **www.legalhelpmate.com/power-of-attorney.aspx**; **www.expertlaw.com/library/estate_planning/power_of_attorney.html**.

Health Insurance Portability and Accountability Act (HIPAA)

HIPAA is a federal law that covers the privacy of your medical information. It also covers issues such as the transfer and continuation of health insurance coverage. We have included a fact sheet in the Appendix for your review. For more information check the US Department of Health and Human Services website at **www.hhs.gov/ocr/hipaa**.



Chapter 6

Cultural Competence and Transition

Chapter 6 Cultural Competence and Transition

Cultural Competence

Cultural beliefs about health and wellness can vary according to one's ethnicity, and these beliefs can influence your interaction with the health care system.

As a young adult, it is important to inform your health care provider if there are any customs that you and your family observe that could affect medical decisions and treatments. The physician should be willing to provide support and encouragement for you to express your beliefs about health and wellness, as well as work with you to assure access to needed services.

When selecting an adult health care provider, you may want to find out if the physician has experience addressing the health needs of patients from different cultures. As a starting point, youth can ask the following questions:

- How are cultural differences valued and recognized by the health provider and their staff?
- Does the health care provider have interpreter services or materials in different languages for individuals who speak little or no English?
- Does the health care provider have policies and procedures for how to serve people with communication difficulties (e.g. hearing loss and/or literacy issues)

Cultural competence is related to the ability of professionals to work cross-culturally. It can contribute to better health by improving communication and building trust.

Health Literacy

"Health literacy is the ability to obtain, process, and understand basic health information and services needed to make appropriate health decisions and follow instructions for treatment. Culture contributes to health literacy because it affects the way people understand and communicate health information.

Young adults, particularly those with disabilities and complex chronic conditions, need health literacy skills in order to be able to manage their own health condition.

Being able to ask questions is necessary to having healthy behaviors and is the key to informed decision making.

Your health and access to care depends largely on whether you can understand and remember the health information you receive.

Health literacy skills have little to do with your education, income, race, or age. People of all ages and educational levels often find it difficult to understand health or medical information. Medical professionals can sometimes to have a "medical language" that can be confusing to the average person.

- Do not be afraid to ask questions if the medical provider says something that you do not understand
- Practice these skills by asking questions and speaking up for yourself

Dealing with the communication gap

Tips for Clear Ways to Talk to Your Doctor

- I will ask 3 questions concerning my health.
- If I want to I will take a friend or family member to help me at my doctor's visit.
- I will take a list of all my medications when I visit the doctor.
- I will ask the pharmacist for help when I have questions about my medicines.

Good Questions to ask the Doctor

- What is my main problem?
- What do I need to do?
- What kind of support is there to help me?
- Why is it important for me to do this?
- How much will this cost?

www.Askme3.org

Disability Etiquette: What youth really want doctors to know

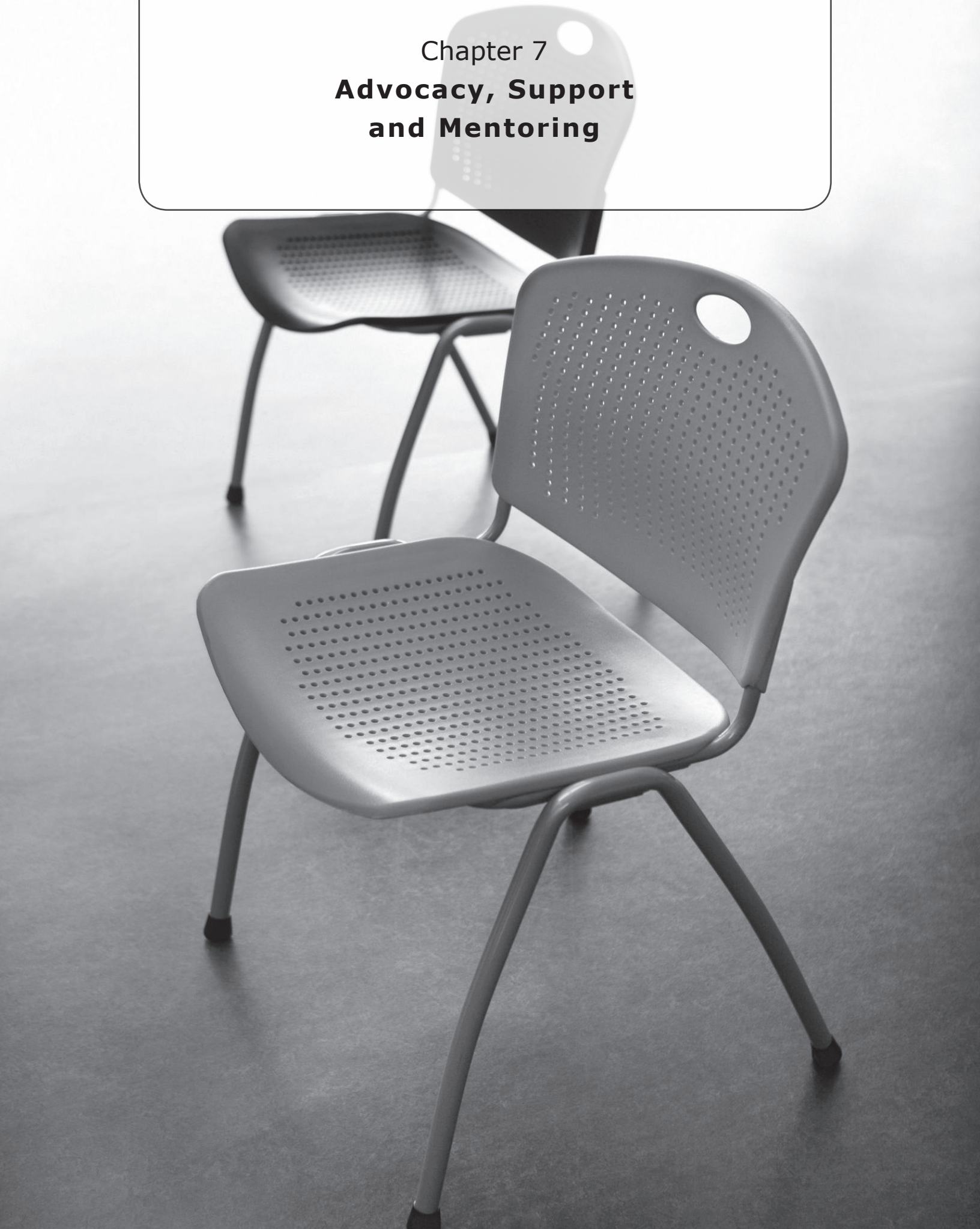
Top Ten List from North Carolina Youth[8]

(In Accordance with David Letterman's Top Ten List)

1. Focus on the problem at hand rather than focusing on personal questions.
2. Compare and contrast alternative treatments and therapies for both emotional and medical issues.
3. Explore and offer low or no cost alternatives.
4. Offer options when possible.
5. Clear and concise answers to all questions.
6. One-stop shop (*medical home approach*).
7. Ask the youth, not the parent or companion.
8. Ask, rather than tell, the youth.
9. Be willing to be open to discussion.
10. Don't underestimate the patient across the disability community.

Chapter 7

Advocacy, Support and Mentoring



Chapter 7 Advocacy, Support and Mentoring

Advocacy Skills for Youth and Young Adults

What is Self-Advocacy?

- Speaking up for yourself
- Asking for what you need
- Negotiating (working with others to reach an agreement that will meet your needs)
- Knowing your rights and responsibilities
- Finding and using resources available to you
    - ➤ Advocacy starts with knowledge: knowledge of medical history (diagnosis), medical needs, patient rights, and personal desires.
    - ➤ One of the best ways to get the skills necessary for transitioning is practice, practice, practice!
    - ➤ Watch for opportunities to talk about advocacy and speaking up for what YOU need.

Practice your advocacy skills and become involved in decisions about your own health care. Some examples of ways to become involved your own health care includes:

- Write letters (drafting what needs to be said or asked)
- Schedule your own medical appointments
- Arrange for your own transportation needs
- Request medication refills from your provider
- Create a list of questions before a medical appointment
- Request accommodations from the doctor when you schedule your medical appointments

Advocacy Skills 101

- Know yourself (self-awareness)
- Getting to know yourself better so you can enjoy a healthy well-rounded adult life.
- Self awareness is building blocks of a healthy life.
- Find out what you want from life or a piece of your life
- Setting a goal
- Problem solving
- Effectively communicate your needs
- Find resources if you need them

On being a self-advocate…

It may be difficult at first, but stick with it and you will succeed.

✦✦*If you reach for the moon you may land among the stars.*✦✦

The stars represent your support team

Remember…don't rely on a friend or family member to ask questions for you on a doctor's visit.

Their role is to support you as a backup.

Be your own advocate!

Finding Support through the Health Care Transition Process

One of the best ways to find support as you begin the process of health care transition is to reach out to other youth who have already experienced this process. There are agencies in North Carolina that can link you with youth with similar backgrounds (same diagnosis, etc.) to share your experiences and provide support for each other.

Support agencies include:

- Alliance of Disability Advocates – Center for Independent Living
- Center for Development and Learning

Additional Support resources

- Other support comes from knowing who you can contact in case there is an emergency.

In Case of Emergency (ICE) Cell Phone Contact List

ICE is a sticker you can put on your cell phone to let people know you have an emergency contact listed in your phone.

You can order ICE stickers to put on your cell phone at **www.icesticker.com**. The website can also provide directions on how to put your emergency contact in your phone.

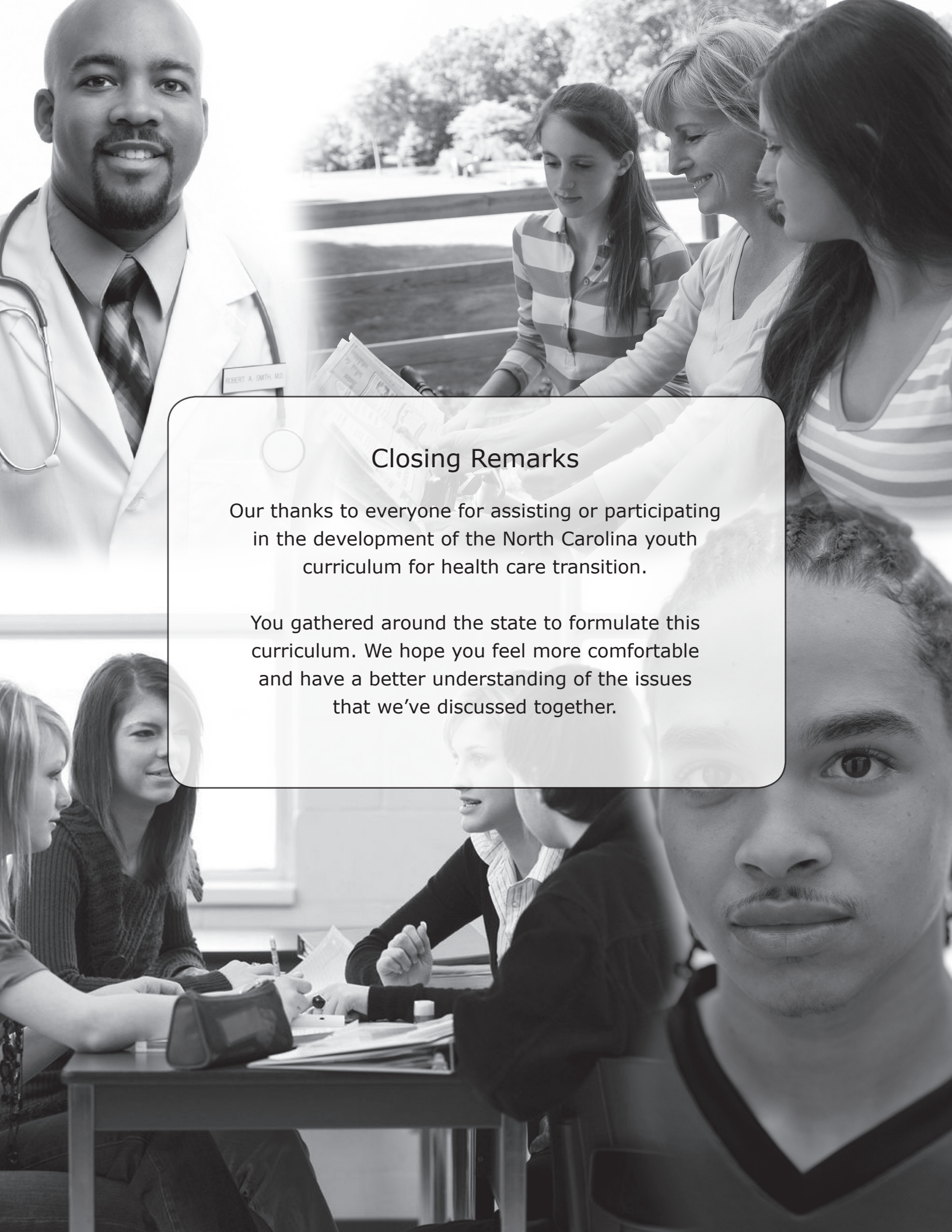
Leadership: Providing Support for Other Youth

Once you are well into the transition process, you may consider offering your valuable experience to other youth who are just starting out. By mentoring other youth, you will have the opportunity to share your knowledge, provide support, and help another teenager much like you.

- Remember while you are building supports for yourself to also seek out other support networks specific to your disability or chronic condition.
- Included are some useful websites for this purpose in the ***Resources*** section of the toolkit.

Our thanks to everyone for assisting or participating in the development of the North Carolina youth curriculum for health care transition.

You gathered around the state to formulate this curriculum. We hope you feel more comfortable and have a better understanding of the issues that we've discussed together.



Closing Remarks

Our thanks to everyone for assisting or participating in the development of the North Carolina youth curriculum for health care transition.

You gathered around the state to formulate this curriculum. We hope you feel more comfortable and have a better understanding of the issues that we've discussed together.

References

1 McPherson, M., et al. (1998). A New Definition of Children with Special Health Care Needs. Pediatrics. 102(1);137-139. www.pediatrics.org/search.dtl]

2 CHOICES Survey, 1997; NOD/Harris Poll, 2000; KY TEACH, 2002

3 www.hrtw.org/hrtwu/ppts/2007HRTW-FL-SESSION-C14-TRANSITION-HACKETT.ppt#19

4 Adapted from: www.youngwomanshealth.org/transitions Children's Hospital, Boston

5 The Medical Home. Pediatrics.2002;110: 184-186

6 Pediatrics 2005;116: 1238-1244; Care Coordination in the Medical Home: Integrating Health and Related Systems of Care for Children With Special Health Care Needs.

7 Pediatrics 2005;116: 1238-1244; Care Coordination in the Medical Home: Integrating Health and Related Systems of Care for Children With Special Health Care Needs.

8 Compiled by Carolina Health and Transition (CHAT) Project, Youth Project, compiled by Caroline Ambrose, Alliance of Disability Advocates ~ Center for Independent Living, Raleigh, NC

Resources

Healthy and Ready to Work
www.hrtw.org

NC Assistive Technology Program
www.ncatp.org

Youth Rights and Responsibilities – A Handbook for North Carolina's Youth
www.doa.state.nc.us

Medical Dictionary Definition of Popular Terms Easily
www.medicinenet.com

Teen Health
www.kidshealth.org/teen

Discovery Health
http://health.discovery.com

PBS Science and Health
www.pbs.org/science/science_health.html

Better information Better Health
www.webmd.com

NC Division of Social Services
www.ncdhhs.gov/dss/local

NC Doctors
www.ucomparehealthcare.com/drs/north_carolina

NC Transit Links
www.apta.com/links/state_local/nc.cfm

Alliance of Disability Advocates serves the following counties:
Durham, Franklin, Johnston, Orange, and Wake (youth initiative)
www.alliancecil.org

Disability Rights and Resources serves the following counties:
Cabarrus, Gaston, Mecklenburg, and Union
www.disability-rights.org

Joy A Shabazz Center for Independent Living serves the following counties:
Alamance, Caswell, Guilford, Randolph, and Rockingham
www.shabazzcenter.org

Pathways for the Future serves the following counties:
Cherokee, Clay, Graham, Haywood, Jackson, Macon, and Swain
www.pathwayscil.org

Western Alliance serves the following counties:
Buncombe, Henderson, Madison, McDowell, Polk, Rutherford, and Transylvania
www.westernalliance.org

The Arc of North Carolina
www.arcnc.org

Exceptional Children's Assistance Center (family initiative)
www.ecac-parentcenter.org

Mountain Area Health Education Center (medical provider initiative)
www.mahec.net

First in Families of North Carolina
www.fifnc.org

North Carolina Division of Public Health
www.ncpublichealth.com

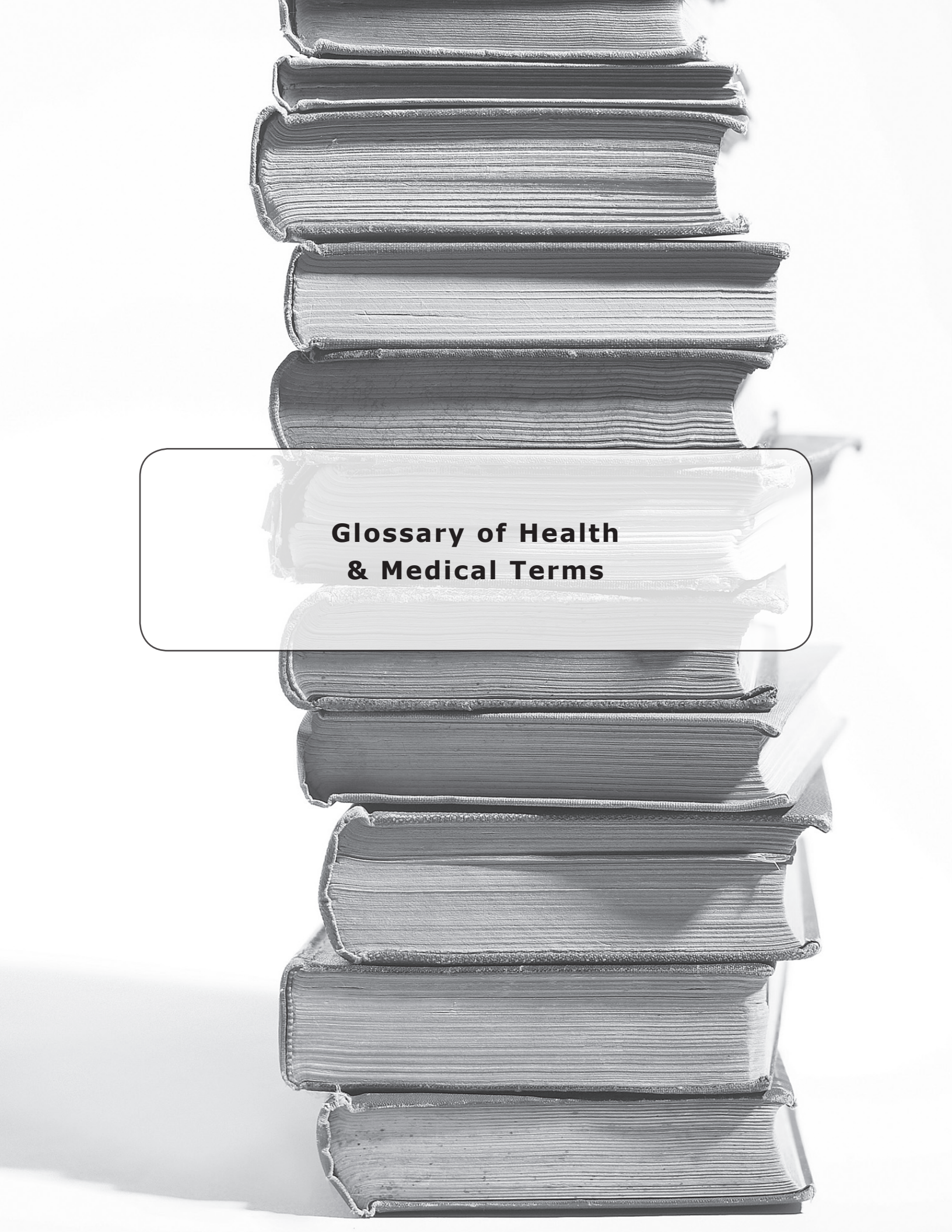
North Carolina Office on Disability and Health
www.fpg/unc.edu/~ncodh

Low Income Health Insurance
www.nchealthystart.org/public/childhealth/index.htm

Social Security Administration
www.ssa.gov

North Carolina Department of Health and Human Services
www.ncdhhs.gov

Self Advocate (Center for Development and Learning)
www.self-advocate.com



Glossary of Health & Medical Terms

Glossary of Health & Medical Terms

Accommodation
A requested change to something to make it easier for someone to complete the task more independently.

Blood Pressure
The force of blood against the walls of the arteries

Blood sugar/glucose test
A test that measures the amount of sugar/glucose in the blood

Blood work/lab work
A medical test that usually uses your blood to see if you have any medical problems

Cholesterol test
A blood test that measures the total amount of fatty substances in your blood; Tests are for three different kinds of cholesterol-LDLS, HDLs, and Triglycerides

Chlamydia
One of the most common sexually transmitted diseases (STDs) in the United States; It is easily spread because it often causes no symptoms and may be passed between sexual partners without knowing it

Co-Pay (Co-payment)
The amount for a medical service/medication that a person pays for in addition to what their insurance covers

CYSHCN – Children and Youth with Special Health Care Needs
Persons up to age 21 who have or are at higher risk for, chronic physical, developmental, behavioral, and/or emotional conditions and need more health and related services than most people need

Diabetes
A condition where you have abnormal levels of sugar/glucose in your blood; There are two different kinds of diabetes – Type 1 also called Juvenile (childhood) diabetes and Type 2 which is adult onset

Emancipation
When a minor becomes independent from his or her parents, often by getting married before reaching age 18 or by becoming fully self-supporting; authorizes you to be treated and to act as an adult; Emancipation age in North Carolina is at least 16

Group Insurance
An insurance plan that includes more than one person

Guardian
A legally selected person who provides assistance on financial and medical decisions

Hepatitis
Inflammation of the liver which can cause jaundice (yellowing of the skin), liver growth, and fever

HDL – High Destiny Lipoprotein
Good cholesterol, which helps remove fat from the body

HIV/AIDS
A disease of the immune system that makes you more likely to get infections and to get sick. HIV is transmitted (carried to another person) through the blood or blood products that enter the body's bloodstream, such as through sexual contact or infected needles. HIV is the disease that causes AIDS

ICE – In Case of an Emergency
These are people that can be contacted in case you have a crisis situation

Illegal Drugs
Drugs that are not legal or are not prescribed to you. For example: marijuana, LSD, cocaine, heroin, morphine, or drugs prescribed to someone else

Illness
Unhealthy condition; poor health; sickness

Immunization
Shots given by a doctor to prevent certain illnesses

Individualized Support
Services specific to the strengths, needs and values of each individual

Living Will
A document listing medical preferences in the event that a person should become unable to make medical decisions on their own behalf

LDL – Low Destiny Lipoprotein
Bad cholesterol; carries mostly fat and only a small amount of protein from the liver to other parts of the body

Medical Insurance card
A card that shows your medical insurance plan, including your insurance company's name, policy number, and date of eligibility; a medical insurance card is needed when you go to the doctor and pick up your prescription at the pharmacy

OTC
Over the counter medications (not prescribed by a doctor)

PCP – *Primary Care Provider*
These are doctors who see people for common medical problems. This person may also be a physician assistant, a nurse practitioner, or a specialist. They are often involved in your care for a long time and provide referrals to other doctors that can assist with your health needs

Pediatricians
Doctors who care for children from birth to early adulthood

Power of attorney
A written document stating that you give permission for another person to make decisions for you, if you are unable to do so

Rectal exam
An exam to find problems that can be felt from within the rectum. The medical provider inserts a lubricated, gloved finger into the rectum and feels for anything that is not normal

Self-determination
The freedom to live as one chooses, making decisions without asking others

Sexual Intercourse
The insertion of the penis into the vagina

Specialists
A doctor that works in a special area of medicine; For example: OBGYN, dermatologist

STD's – Sexual Transmitted Diseases
These are contagious diseases a person can get during sexual contact

Support staff
A paid person(s) who provides individualized services, and generally has the following qualities:

1. are effective, efficient and courteous;
2. are creative and proactive;
3. maintain confidentiality;
4. work together with an individual and with other key members of the support team;
5. listen to needs and help find solutions;
6. respond positively to feedback;
7. provide equity of access;
8. continuously improve service, skills and knowledge

Test
Laboratory and screening assessments given by your doctor

TBD
To be determined

Triglycerides
Type of fat the body uses to store energy

Ward
A person that makes money and medical decisions for you

Wellness
The fact or condition of being in best physical and mental health; commonly referred to as checkup or a physical

Will
A legal declaration of a person's wishes as to the disposition of his or her property and/or estate (land) after death; the will is usually written and signed by the testator and attested by witnesses

X-rays
Uses a very small amount of radiation (light) to produce an image of the bones and tissues surrounding a joint