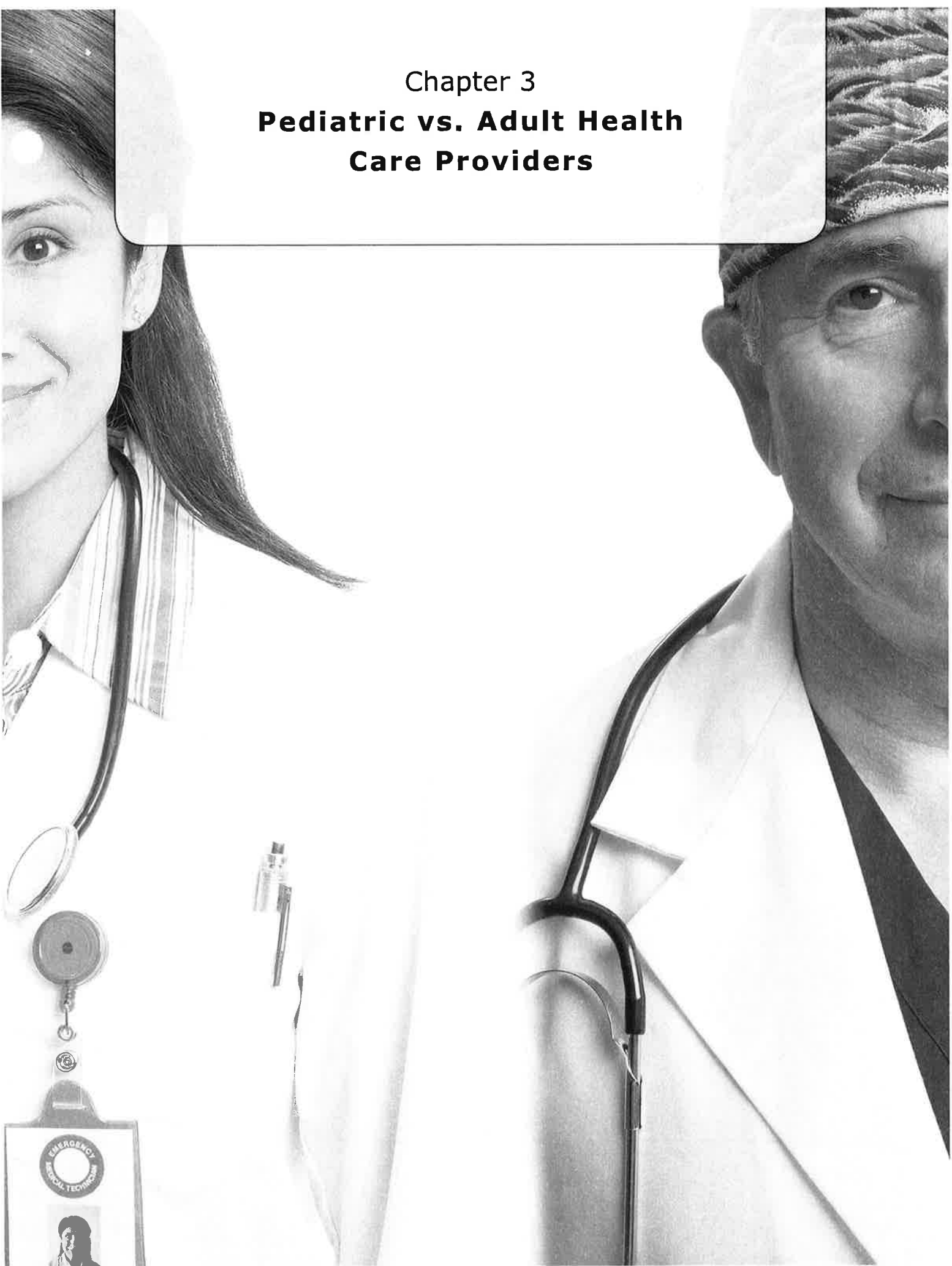


Chapter 3
**Pediatric vs. Adult Health
Care Providers**



Roles and Responsibilities of Health Care Providers

Make sure the pediatric provider is involved in educating your child about lifelong transition skills such as proactive planning, problem solving, self-advocacy, and negotiation.

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.

As a parent of a youth (teenager) with special needs you should discuss their concerns and priorities and how the changes these may change as they are going through the transition process.

Share assessment tools (checklists, etc.) with your child's provider that you have completed with your child. This will give the provider a good idea about how to support your family through the health care transition process.

Support Services and Ongoing Education

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

Their role in the health care transition process should include:

- Provide preventative care and teach healthy lifestyle choices
- Identify and treat common medical conditions
- Assess the importance of medical problems and give proper direction for that care
- Provide information on insurance options as an adult

Where to find and how to search for additional resource materials

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

Please see the **Resources Section** for more information.

Record keeping

While working with your youth's 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 youth's important medical treatments, you can provide them with enough information to help them transition to the adult health care provider at the appropriate time.

Teaching your youth to maintain their own records will also support their 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 care coordination (Care Notebook, see page 22)
- Use a portable medical summary (see page 61)

Skill Building Activity

Suggested record-keeping methods: Care Notebook and Portable Medical Summary

Care Notebook

- Should be complete and current
- Keep multiple copies (in case another doctor needs the information)
- Includes medical history, disability information, past records (keep at home)

The following section includes information from a website page on how to build your own care notebook. By using the tools on this website, you will be able to pick and choose the pages that are important for your youth's specific needs.

Portable Medical Summary

- 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** and a blank one for you to complete with your youth is included in the **Toolkit**. An electronic version can also be accessed at www.hrtw.org.

Take this opportunity to work together with your youth on each of the methods of record-keeping. This will strengthen your youth's knowledge about his or her history and condition but will also prepare him or her to become responsible for their own health information.

Building Your Own Care Notebook

Below is a list of downloadable forms that can be used to build your own **Care Notebook**. You may download a complete section's documents by clicking on the section's ZIP link, or select specific documents by clicking on the sub-category links below. All Care Notebook forms are made available in both **Microsoft Word** and **Adobe PDF** versions for your convenience.

Complete List of Forms Available: www.medicalhomeinfo.org/CareNoteBook

Care Notebook Cover Page

Personal Information

- Care Providers
- Insurance Information
- Family Information
- Family Support Resources
- Funding Resources

Pages to Keep Track of Appointments and Care

- Appointment Log
- Diet Tracking Form
- Equipment-Supplies
- Growth Tracking Form
- Hospital Stay Tracking Form
- Immunizations
- Information Needed by Emergency Care Providers
- Lab Work-Tests-Procedures
- Make-a-Calendar
- Medical Bill Tracking Form

- Medical-Surgical Appointments
- Medications
- Family and Child Medical History

Personal Notes

- Parent and Child Questions for Doctor
- Parent and Child Questions for Setting up Home Care

Care Needs of My Child's Abilities and Special Needs

- Activities of Daily Living
- Care Schedule
- Child's Page – Now and Later
- Communication
- Coping-Stress Tolerance
- Mobility
- Nutrition
- Respiratory
- Rest-Sleep
- Social-Play
- Emergency Plan
- Baby-sitters Guide
- Information for Caregivers-Instructions for Care

Community Health Care-Service Providers

- Medical/Dental
- Public Health

- Home Care
- Therapists
- Early Intervention Services
- Child Care
- Respite Care
- Pharmacy
- Special Transportation

School Issues

- School: Making it work
- Home-School Worksheet
- School Communication Sheet
- Permission for Procedures-Medications at School
- Physical Education Activity Guide
- Insert your Individual Education Plan or 504 Plan
- Transitions-Looking Ahead

Roles of Care Coordinators

Care coordination helps link children and their families with appropriate services and resources in a coordinated effort to achieve good health.

The Care Coordination Process⁴

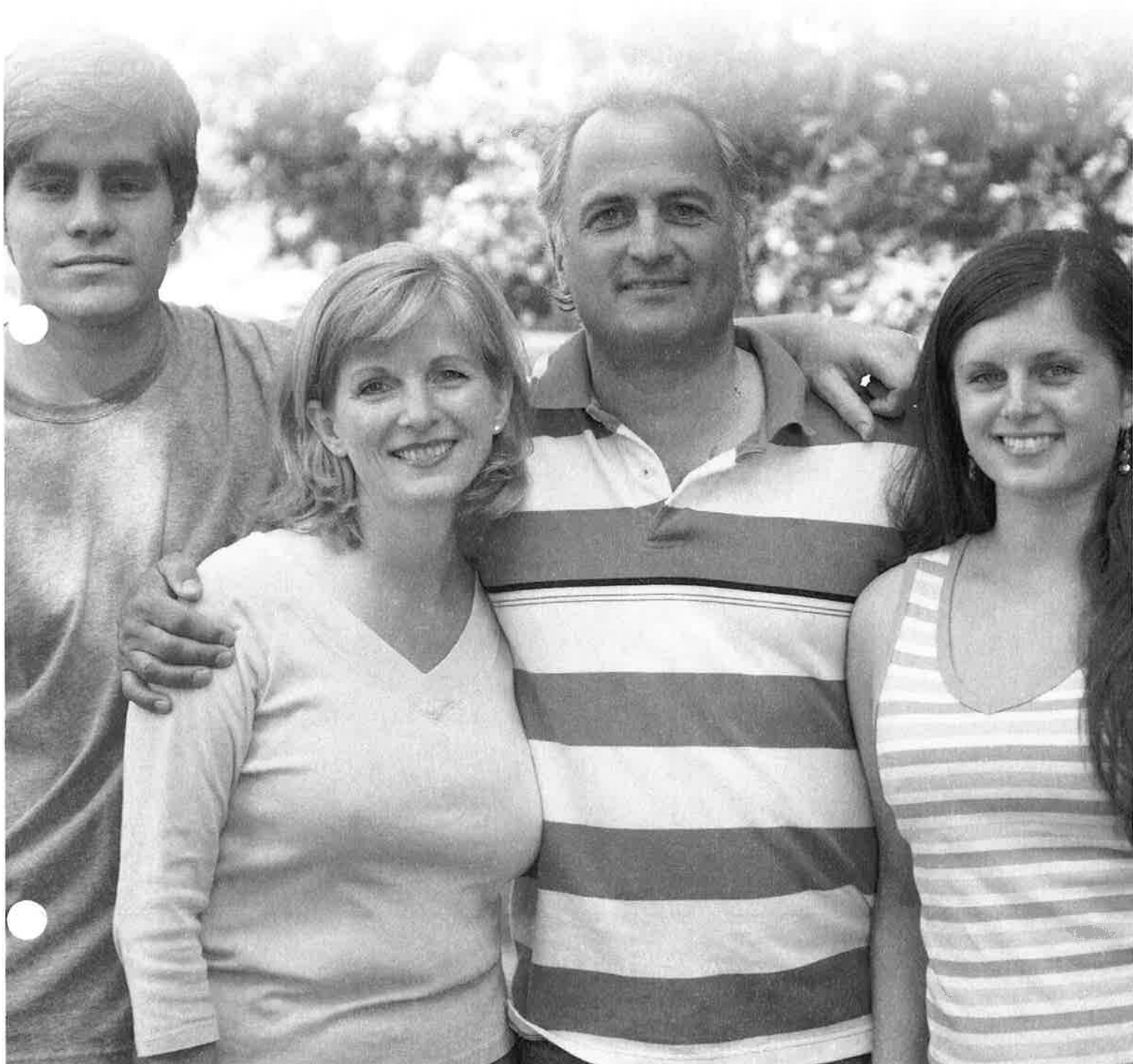
1. **Assess and Identify Needs** – Activities performed by a care coordinator are based upon a comprehensive assessment that can sometimes include

a psychosocial assessment of the child 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 plan of care.

- 2. Develop a Plan of Care** – After identifying the needs, a plan of care is developed with the family when goals and outcomes are discussed. The care coordinator may clarify with the family which action steps the family will address and which will be addressed by the care coordinator.
- 3. Put the plan into action** – Following the plan, take actions to work towards the desired outcomes. Identified service providers and programs all work towards fulfilling the needs of the family. The care coordinator organizes the process and helps the family with resources, referrals, and coordinating care with specialty physicians, with schools and other agencies.
- 4. Evaluate** – Periodic evaluations are performed to reassess the plan of care and to address new needs.

Ask your child’s 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.

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 the health and medical needs of your youth as they enter adulthood.

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

An example of topics to consider include:

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

It is important that your child provides his/her **valuable input** during the creation and maintenance of this document.

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

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 child's 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

**Check the Toolkit for Sample
Transition Care Plans!**



Chapter 5
**Health Care Coverage
and Legal Issues**



Health Care Coverage for Adults with Disabilities

In many states, as soon as a youth becomes 18 years old, the eligibility requirements for health insurance change. 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 options that may be possible for your youth, based on their health condition and medical necessity.

Best advice: Start early and plan ahead!

Age Restrictions for Private Insurance (North Carolina)

It is important to note that, in the state of North Carolina, health insurance coverage for your child with special health care needs can be maintained even after he or she reaches the age at which dependent child coverage usually terminates, usually age nineteen (19).

Your child's status as a student is **not** a consideration. In order to qualify for this continual insurance coverage, the child must be incapable of sustaining employment because of mental retardation or physical handicap and must be chiefly dependent on the policyholder (or subscriber) for support and maintenance.

The policyholder or subscriber (youth/young adult) must provide proof of incapacity (inability) and dependency to the insurer, hospital service plan, or medical service plan corporation within 31 days of the youth reaching the age limit.

You (parent or caregiver) may also be required to furnish proof of this incapacity or dependency as required by the insured (but not more frequently than annually) after the child has reached the age limit.

If you need to reference this information, it can be found under **N.C. General Statute 58:51:25⁵**.

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 both the privacy of your youth's medical information as well as issues related to the transfer and continuation of health insurance coverage. We have included a fact sheet in the Toolkit for your review. For more information check the US Department of Health and Human Services website at www.hhs.gov/ocr/hipaa.

Family Educational Rights and Privacy Act (FERPA)

FERPA is another federal law that deals with access to educational records, as well as health records held at educational institutions. Please review the fact sheet in the Appendix. A brochure for parents can be found on the US Department of Education website: www.ed.gov/policy/gen/guid/fpco/brochures/parents.pdf.

Guardianship

There are many factors to consider when deciding guardianship. A guardianship is the legal proceeding by which a capable adult (e.g. agent) can be appointed to manage the personal or financial affairs of an individual who is unable to do so on his or her own. As a parent, the best resource for obtaining more information is to visit the NC Guardianship Association at www.nc-guardian.org.

**Check the Toolkit for more Information
on Insurance Tips and Resources !**

Chapter 6
**Cultural Competence
and Transition**



Cultural Competence

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

As a parent, it is important to inform your youth's doctor if there are any customs that your family observes that could affect medical decisions and treatments. The physician should be willing to provide support and encouragement for you to express your families' beliefs about health and wellness, as well as work with you to assure access to needed services.

When selecting an adult health care provider, your youth may want to find out if the physician has experience addressing the health needs of patients from different cultures.

As a starting point, the family member or 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 individuals with communication difficulties (e.g. hearing impairment 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.

Families of all youth, particularly those with disabilities and complex chronic conditions, need health literacy skills in order to be able to manager their youth's health condition.

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

You and your child's health depends largely on whether you can understand and remember the health information you receive.

A recent government study estimates that over 93 million American adults have limited health literacy skills. This number may be somewhat higher because most patients often hide their confusion from their doctors because they are too ashamed and intimidated to ask for help.⁶

Health literacy skills have little to do with a person's education, income, race, or age. People of all ages and educational levels often find it difficult to understand health or medical information. Medical professionals seem 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
- Be a good role model for your child by asking questions but also by encouraging them to ask for themselves

**Check the Toolkit for more information
about Health Literacy!**

Chapter 7
**Advocacy, Support
and Mentoring**



Advocacy Skills for Parents

An **advocate** is someone who speaks out for a person or a cause. How you advocate for your children's health care needs when they are young, teaches them to advocate for themselves as they become teenagers or young adults.

Advocacy starts with knowledge: knowledge of medical history (diagnosis), medical needs, patient rights, and personal desires. One of the best ways to provide your child with the skills necessary for transitioning is practice, practice, practice!

Watch for opportunities to talk about advocacy and speaking up for what they need. Be a good advocacy model. Some examples of ways to involve your child in her or his own health care include having the child:

- Write letters (drafting what needs to be said or asked)
- Schedule his or her own medical appointments
- Arrange for her or his own transportation needs
- Request medication refills from his or her provider
- Complete a list of questions before a medical appointment

Let youth try to advocate for themselves with you there to support. Encourage them to talk about their health conditions and how they feel. Teach them to communicate with medical providers; redirect questions from the provider to your child.

Advocating goes beyond one's personal and immediate needs. It also includes being involved in system-wide changes through legislation.

- Are you aware/involved/active in local/state/national system change advocacy?
- Has your youth been given an opportunity to experience this kind of advocacy?

Finding Support through the Health Care Transition Process

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

Support agencies include:

Arc of NC
(800) 662-8706

Exceptional Children's Assistance Center
(800) 962-6817

Family Support Network
(800) 852-0042

Mentoring: Providing Support for Other Families

Once your family is well into the transition process with your child, you may consider offering your valuable experience to other families who are just starting out. By mentoring other families you will have the opportunity to share your knowledge, provide support, and help a family much like yours.

- Remember while you are building supports for yourself to also seek out support networks for your child
- Included are some useful websites for this purpose in the **Resources** section of the toolkit

**Check the Toolkit for information about building
a Circle of Friends and other support networks!**

References

- 1 CHOICES Survey, 1997; NOD/Harris Poll, 2000; KY TEACH, 2002
- 2 The Medical Home. Pediatrics.2002;110: 184-186
- 3 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.
- 4 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.
- 5 NC Family to Family Health Information Center Fact Sheet 6. Private Health Insurance. 11/21/06
- 6 American Medical Association - AMEDNEWS.COM
www.ama-assn.org/ama/pub/category/8115.html

