Health and Medical Issues for Transition-age Adolescents with Disabilities and/or Health Care Needs:

A Guide for Teenagers and Their Families (2nd edition)

Human Development Center
Louisiana’s University Center of Excellence in Developmental Disabilities Education, Research, and Service
LSU Health Sciences Center
Health and Medical Issues for Transition-age Adolescents with Disabilities and/or Health Care Needs: A Guide for Teenagers and Their Families (2nd edition)

Written by:

Meg Pomeroy, R.N.
Children’s Hospital
New Orleans, LA

Jane M. Everson, Ph.D. and Joan D. Guillory, M.Ed.
Human Development Center (HDC)
Louisiana State University Health Sciences Center (LSUHSC)
New Orleans, LA

Amy L. Fass, MPH
Children’s Special Health Services
Office of Public Health
Department of Health and Hospitals
New Orleans, LA

Louisiana: Healthy and Ready to Work (LHRW)

October 2001

LSUHSC does not discriminate on the basis of race, color, national origin, sex, religion, age, or disability in employment or in the provision of services.

This document is a revised and updated version of a product originally supported by funds from the U.S. Department of Health and Human Services, Maternal and Child Health Branch (Grant # MCJ-22HRW6, “Louisiana: Healthy and Ready to Work”). The opinions expressed herein are solely those of the authors and do not necessarily reflect the positions or policies of the U.S. Department of Health and Human Services, and no official endorsement should be inferred. This guide may be reprinted only with written permission from Dr. Jane M. Everson, Human Development Center, LSUHSC, 1100 Florida Avenue, Building 119, New Orleans, LA 70119-2799.
Acknowledgements

The authors wish to thank the hard-working members of the Health and Medical Work Team of Louisiana: Healthy and Ready to Work for their dedication and efforts. Specifically, we wish to thank Brenda Brown, Brenda Singelmann, Debbie Dequeant, Zelma Malone, Jan Mayeaux, LaVonne Smith, and Nora Steele.

In addition, we wish to acknowledge the excellent formatting skills and superior graphic contributions of both Trent Oubre and Rhitt Growl.

Lastly, we wish to thank Mr. Tom Gloss, our LHRW Project Officer, for his support throughout our project.
# Contents

## CHAPTER ONE
Why are Health and Medical Issues an Important Part of Transition Planning with Teenagers? ........................................... 1

- Transition Planning .................................................. 2
- Creating a Health and Medical Map .......................... 4
- Summary ........................................................................ 8

## CHAPTER TWO
Preparing for Independence at Home, at School and in the Workplace ............................................................... 9

- What is Independence? .............................................. 9
- Typical Adolescent Experiences, Health and Medical Needs, and Strategies for Encouraging Independence ......... 10
- What is the Family’s Role in Encouraging Health and Medical Independence? ......................................................... 12
- Summary ........................................................................ 12

## CHAPTER THREE
Paying for Health and Medical Care .............................................. 17

- Private Insurance .................................................. 17
- Medicaid ............................................................... 18
- Helpful Hints .......................................................... 18
- Summary ........................................................................ 19
CHAPTER FOUR
Choosing and Working With Health and Medical Providers ............. 20
Overview of Health and Medical Providers and Specialists .................. 20
Selecting Health and Medical Care Providers ....... 23
Managing Health and Medical Needs ................ 27
Helpful Hints........................................................... 34
Summary................................................................. 35

CHAPTER FIVE
Self-determination in Health and Medical Care ....................... 36
What is Self-determination?........................................ 36
Assessing Self-determination in Health and Medical Care .................. 37
Strategies for Developing Self-determination in Health and Medical Care ........................................... 37
Summary ...................................................................... 39
Contents

CHAPTER SIX
Living a Healthy Lifestyle ......................................................... 40

What is a Healthy Lifestyle? ................................................. 40
Basic Ingredients of a Healthy Lifestyle ......................... 41
Summary ................................................................................. 52

APPENDICES .......................................................................... 53

A. Glossary of Health and Medical Terms ............ 53
B. Listing of Self-determination Curricula ............. 63
C. Helpful Health and Medical Resources .......... 71
D. Health and Medical Provider Feedback
Postcards .............................................................................. 74
CHAPTER ONE

Why are Health and Medical Issues an Important Part of Transition Planning with Teenagers?

Transition means movement and change. Adolescence is a time of many transitions, such as moving from a high school setting to a college setting and/or changing from a student’s roles to an employee’s roles. It is also a time of movement from a pediatric system of health and medical care to an adult system and changing from a child’s roles to an adult’s roles.

Transition is a time of risk-taking, a normal characteristic of adolescent development. Risk-taking behaviors allow adolescents to search for independence and autonomy. However, it is important to differentiate between normal and healthy risk-taking behaviors and those behaviors that are atypical and destructive. In addition, some behaviors may be more unhealthy and destructive for teenagers with disabilities and/or special health care needs than they are for typical adolescents.

Research shows that when adolescents take risks, they generally do not stop with one. That is, if they try smoking, they may also try alcohol. If they try one criminal activity, they may also try another. Experts generally agree that teenagers and their families need to discuss risk-taking and decision-making as opposed to individual behaviors. Adolescents who are allowed and encouraged to take healthy risks, discuss them with family members and trusted adults, and make decisions about the outcomes of the risky behaviors are more likely to learn self-regulation behaviors.

Transition is also a time of decision-making in sensitive areas, such as sexual and reproductive health, nutrition, fitness, financial and estate planning, employment, post-secondary education, and independent living. Teenagers must make many decisions as they prepare to leave high school and transition to employment, post-
secondary education and/or living on their own. They and their families may be overwhelmed with information and the need to answer questions that will impact how they make important decisions about the future.

“Will I be able to go to college or vocational school?”
“Where will I live and with whom?”
“Will I be able to work?”
“Where will I work?”
“Will I marry and have children?”

Thinking about the answers to these and other questions is not easy for any teenager, but for those with disabilities and/or special health care needs, finding the answers to these questions may raise even more questions and result in fear, anger, frustration, and confusion.

“If I find a job without health insurance, will I lose my Medicaid?”
“What if I have a seizure at work?”
“Who will help me dress and bathe if I move away from home?”
“Where will I go to get my wheelchair repaired?”
“If I have children, will they have my disability?”

Planning can help teenagers and their families think about and answer their questions, set goals, and make plans, thus making the transition time period more successful and less stressful. The purpose of this guide is to help teenagers with disabilities and/or special health care needs and their families think about, discuss, and plan for the many transitions teenagers face as they prepare to transition from high school to adult life.

**Transition Planning**

Formal transition planning should begin between the ages of 14 and 16 and continue until the young adult leaves high school and even beyond high school. Between the ages of 14 and 16 years, all teenagers with disabilities and/or special health care needs who receive special education services under the **Individuals with Disabilities Education Act (IDEA)**, as amended, will be asked each year to develop a **statement of transition services** as part of their **IEP** (Individualized Education Program). This statement, which may also be known as an Individualized Transition Plan or **ITP**, helps teenagers and their families think about and set goals for employment, post-secondary education and independent living. The transition plan should also help them think about and set goals around transportation needs,
leisure interests, financial and legal concerns, and health and medical needs.

Thinking and talking about health and medical issues are essential parts of comprehensive transition planning, but they are often overlooked or given only a few minutes of attention during IEP meetings. This may be because health and medical questions are considered very personal, something to be discussed at home and not at school. Or, perhaps teachers, therapists, and counselors are unaware of the teenager’s and/or family’s questions, fears, and concerns, assuming that if they have questions they will ask them. Or, it may be because teenagers are uncomfortable asking questions about personal and sensitive issues during formal IEP team meetings in the presence of their parents, teachers, therapists, and/or counselors. Whatever the reasons, the health and medical needs of these teenagers are not usually discussed in detail during IEP and transition planning meetings.

Many teenagers with disabilities and/or special health care needs successfully attend high school without receiving any special education services. These students do not have IEPs or statements of transition services and thus do not experience formal transition planning. Their parents, teachers, therapists, counselors, and/or physicians may address their questions and concerns, but all too often and for the same reasons given above, planning for their transition from pediatric health and medical services to adult health and medical services is also overlooked or given only minimal attention.

Whether formal transition planning occurs or not, all adolescents, with or without disabilities and/or special health care needs, are expected to transition from the pediatric health care system to the adult health care system beginning around age 18. This transition may be delayed in special circumstances, such as for those adolescents with significant or multiple disabilities and/or chronic health care needs. At some point, however, the transition must take place.

It is essential for the teenager to be a member of any team that makes decisions about his or her transition. The very best transitions will occur when the teenager, family, pediatric health care providers, educational personnel, and adult health care providers develop a systematic plan for the transition. Ideally, this planning will begin by age 14 or 16 (to coincide with the development of a statement of transition services for those students for whom an IEP is appropriate) and allow ample time for the teenager and family to develop knowledge, set goals, and build greater skills for independence and informed decisions about adult options. Ideally, transition planning will also take place across multiple school years, resulting in implementation of a comprehensive and longitudinal plan.
Creating a Health and Medical Map

Thinking about, talking about, and planning for transition are important for all teenagers as they prepare to leave high school. In Louisiana, as in most states, teenagers reach the age of majority at age 18. This means that they have a legal right to make all decisions, including health and medical decisions, and are assumed to have the knowledge and skills to do so. Some families who have children with very severe disabilities will have concerns about the young adult’s ability to make health and medical decisions and may choose to limit some or all of the decisions available to him or her through legal processes, including through a process known as interdiction or through establishing a medical power of attorney. Even when this is so, planning must consider health and medical care needs and personal preferences. All teenagers with disabilities and/or special health care needs will benefit from comprehensive transition planning that includes attention to their health and medical needs.

A good foundation for this plan is the IHP (Individualized Health Plan) developed by the school nurse for those teenagers with special health care needs. Another good foundation is the health and medical records gathered by teenagers, their families, and their pediatric care providers. A third good foundation is completion of activities typically endorsed by any of the commercially available self-determination curricula designed for adolescents. (See Appendix B for a listing of the most common self-determination curricula.) These materials can be used to stimulate discussion about risk-taking behaviors, to assist in gathering information regarding needed and desired health plans and supports for life after high school, and to design plans that encourage and support the teenager to gradually take more responsibility for goal-setting, decision-making, and self-monitoring. Planning may be done at school, at home, in a clinic or doctor’s office, during support or self-advocacy group sessions, or all of the above!

A health and medical map is a graphic portrayal of assessment and planning information gathered and organized by teenagers, their families, and service professionals. The purpose of a health and medical map is to encourage teenagers and families to think about and share their health and medical concerns, to plan and set goals for their wants and needs, and to organize the information in a way that allows them to take charge of their futures. Figure 1.1 is a set of questions many teenagers, their families, and teachers have found helpful as they begin mapping their health and medical wants and needs. Teenagers and their families are encouraged to think about and discuss these questions and to use the young adult’s answers to identify wants and needs to be addressed in the appropriate
Why are Health and Medical Issues an Important Part of Transition Planning with Teenagers?

Questions to Think About:

DEVELOPING A HEALTH AND MEDICAL MAP

1. What does “healthy” mean to you?

2. What are some of the things you do that help to keep you healthy? What are some of the things you do that may lead to poor health or may be a health or medical concern?

3. Do you take any medications or treatments? If yes, what are they and what are they for? How often do you take them? Are there any side effects that you need to think about in planning your day?

Figure 1.2 is an example of a map created by one teenager with diabetes. This map is presented only as an example; teenagers will want to create their own maps using any format they choose. For example, some teenagers may choose to cut words and pictures out of magazines to illustrate their wants and needs, whereas others may define written personal goals and the actions needed to accomplish the goals. The selected format is unimportant; what is important is spending the time thinking about and discussing the questions, identifying one’s wants and needs, and setting goals and actions to assume more responsibility for managing one’s health and medical care.
4. Do you take these medications or treatments independently or do you need assistance? If you need assistance, what kind and how much?

5. Do you have any other health and medical needs that may affect the planning of your day? If yes, what are they?

6. What agencies and people can help you with health and medical needs? Do you know what questions to ask to obtain the information and services you want and need?

7. Are you comfortable with your abilities to direct the agencies and people who provide you assistance? If no, what would make you more comfortable?

8. (As appropriate) Do you know how to care for and repair your assistive equipment?

9. Do you have a doctor? Do you have a dentist?

10. Do you have private medical insurance? Do you have Medicaid or Medicare? Do you have dental insurance? How do you keep up with your medical records?

11. How do you handle anxiety or stress?

12. What supports do you need from family, friends, and others to feel healthy and ready to work?
Behaviors/Characteristics That Enhance My Health and Independence...

- I understand my diabetes well.
- I prepared a report on diabetes for my 10th grade biology class.
- I am comfortable letting my friends know I have diabetes; they know what symptoms they should be on the lookout for and how to address them.
- I am comfortable wearing my medical alert bracelet.
- I play basketball and run track.
- I enjoy exercising and plan to continue sports in college and after.
- I have handled my insulin needs almost independently since I was about 12 years old.

Behaviors/Characteristics That Need Support/Put My Health and Independence at Risk...

- I smoke 3-4 cigarettes a week when I am hanging out with the guys on weekends.
- I would like to be completely independent from Mom in handling my medical appointments.
- I want Mom to quit nagging me about my insulin, diet, and smoking.
- I don’t always eat the foods I should. Once I leave home for college, I need to be more aware of choosing and preparing appropriate foods.
- I worry (a little bit) about peer pressure and stress at college, especially around alcohol.
Summary

Transition planning is a long-term process that should begin in early adolescence so that teenagers and their families can begin to think about and discuss life after high school. It usually begins with discussions about employment, post-secondary education, and/or independent living. As these discussions proceed, it is important to begin thinking about and discussing health and medical wants and needs and how they might impact desired adult dreams. Chapter Two will help teenagers and their families continue their thinking and discussion by describing some typical adolescent experiences, related health and medical needs, and strategies for addressing these needs.

A health and medical map, like a road map, provides directions to get you where you want and need to go.
Preparing for Independence at Home, at School, and in the Workplace

One of the primary developmental tasks of adolescence is developing a degree of independence from parents, teachers, and other caregivers. For most adolescents, certain milestones - getting a job, earning money, driving a car, moving away from home, and relying more on peers than parents - define independence. Adolescence is a time of tremendous physical, emotional, and social changes for most teenagers, and having disabilities and/or special health care needs may make the quest for independence more difficult. Teenagers may ask themselves and their families many questions. “Am I different from other teenagers?” “How will my disability and health affect my independence at school, with friends, in marriage, at work, in living arrangements, with transportation, and with parenting?” For most teenagers with disabilities and/or special health care needs, it is impossible to think about their independence at home, at school, or in the workplace without also considering their independence in their health and medical needs.

What is Independence?

Independence means that people have the knowledge and skills to communicate and to act in ways that they choose, without feeling pressure from other people to behave in certain ways or without needing extraordinary help from other people. Independent adults make decisions about where to work and where to live. They make decisions about how to spend their free time and with whom to spend it. They make decisions about when to seek medical consultation and from whom to seek it. Most adults, including many adults with disabilities and/or special health care needs live, go to school, and work with very little help from others. They are independent at home, at school, and in the workplace.
Independence does not mean never needing help to complete an activity or never making decisions without assistance from others. However, it does mean being confident and knowledgeable enough about oneself to make decisions and take action, but also knowing when to ask for help and whom to ask it from. During the transition time period, all teenagers and their families will have questions, fears, and a need to make sensitive and personal decisions during the teenager’s journey toward independence.

**Typical Adolescent Experiences, Health and Medical Needs, and Strategies for Encouraging Independence**

Understanding adolescence and the experiences of typical teens may help everyone understand how teenagers are alike, how they are different, and how they can become as independent as possible. Medically, adolescence begins with the growth and hormonal changes associated with sexual maturity and ends when this growth ends. Educationally, adolescence is typically considered to begin with the start of middle school or junior high and end with the graduation or exit from high school. Legally, adolescence ends when a teenager reaches the legal age of majority. Therefore, independence is a long-term goal to work towards as children move into adolescence and on into adulthood.

Table 2.1 illustrates typical adolescent experiences and related health and medical needs, along with suggested strategies for encouraging health and medical independence. Table 2.1 is just a framework; it is important to remember that all teenagers are individuals and they may express their wants and needs at an earlier or later age and need more or less support to achieve independence in their health and medical needs.

---

**The quest for independence is one of the major tasks of adolescence. For most teenagers with disabilities and/or special health care needs, it is impossible to think about their independence at home, at school, or in the workplace without also considering their independence in their health and medical needs.**
<table>
<thead>
<tr>
<th>TYPICAL ADOLESCENT EXPERIENCES</th>
<th>RELATED HEALTH AND MEDICAL NEEDS/STRATEGIES FOR ENCOURAGING INDEPENDENCE</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Physical Changes</strong></td>
<td></td>
</tr>
<tr>
<td>• Growth Spurts</td>
<td>Are there any developmental considerations associated with specific disabilities, syndromes, or medical conditions?</td>
</tr>
<tr>
<td>• Increased Body Hair</td>
<td>Do changes in height/weight require changes in medication or treatment?</td>
</tr>
<tr>
<td>• Changes in Body Size and Shape</td>
<td>Is there a need to discuss sexual/reproductive health questions/concerns?</td>
</tr>
<tr>
<td>• Changes in Sexual/Reproductive Organs</td>
<td>Is there a need for skill training for new hygiene skills, for example, shaving, use of deodorant, menstrual care, etc.?</td>
</tr>
<tr>
<td>• New Hygiene/Self-Care Needs</td>
<td>Is there a need to discuss the roles of Personal Care Attendants (PCA’s)/other professionals in assisting with hygiene/self-care needs?</td>
</tr>
<tr>
<td><strong>Emotional Changes</strong></td>
<td></td>
</tr>
<tr>
<td>• Increased Sexual Feelings and Interests</td>
<td>Is there a need to discuss sexual/reproductive health questions/concerns?</td>
</tr>
<tr>
<td>• Need to Understand/Handle New Emotions</td>
<td>Is there a need to discuss appropriate/inappropriate touching/sexual abuse?</td>
</tr>
<tr>
<td></td>
<td>Is there a need to discuss feelings of depression/suicide?</td>
</tr>
<tr>
<td></td>
<td>Is there a need to discuss/role play dating behaviors/etiquette?</td>
</tr>
<tr>
<td><strong>Social Changes</strong></td>
<td></td>
</tr>
<tr>
<td>• Learning to Interact with Peers</td>
<td>Is there a need to discuss/role play dating behaviors/etiquette?</td>
</tr>
<tr>
<td>• Learning to Interact with Parents/Other Adults</td>
<td>Is there a need for alcohol/substance abuse education?</td>
</tr>
<tr>
<td>• Establishing Personal Values/Beliefs</td>
<td>Is there a need to discuss/role play workplace behaviors/etiquette?</td>
</tr>
<tr>
<td></td>
<td>Is there a need to discuss family, peer, and personal values/beliefs?</td>
</tr>
<tr>
<td></td>
<td>Are their cultural/ethnic values/beliefs that need to be taken into consideration?</td>
</tr>
<tr>
<td><strong>Intellectual Changes</strong></td>
<td></td>
</tr>
<tr>
<td>• Ability to Think More Abstractly</td>
<td>Is there a need to discuss/support the growth of self-determination skills/behaviors?</td>
</tr>
<tr>
<td>• Ability to Engage in More Problem-Solving/Decision-Making</td>
<td>Is there a need to address educational curricula, courses, and postschool goals?</td>
</tr>
<tr>
<td>• Ability to Self-Manage Resources</td>
<td>Is there a need to address necessary supports to ensure post-secondary educational success?</td>
</tr>
<tr>
<td></td>
<td>Is there a need to provide additional training/experiences in, for example, money management, medication management, etc.?</td>
</tr>
<tr>
<td></td>
<td>Is there a need to provide appropriate and mutually-agreed-upon opportunities for risk-taking?</td>
</tr>
<tr>
<td></td>
<td>Is there a need to provide opportunities to interact with adult mentors with similar disabilities and/or special health care needs?</td>
</tr>
<tr>
<td><strong>Nutritional Changes</strong></td>
<td></td>
</tr>
<tr>
<td>• Interest in/Need for Athletics/Exercise Routines</td>
<td>Is there a need to discuss athletics/exercise interests/adaptation needs?</td>
</tr>
<tr>
<td>• Learning to Make Nutritional Choices</td>
<td>Are there any nutritional considerations associated with specific disabilities, syndromes, or medical conditions?</td>
</tr>
<tr>
<td></td>
<td>Is there a need to discuss nutritional needs/independent grocery shopping/meal preparation?</td>
</tr>
<tr>
<td></td>
<td>Is there a need to discuss eating/weight management behaviors?</td>
</tr>
</tbody>
</table>
As previously noted, it is important to remember that all teenagers are individuals and they may express their wants and needs at an earlier or later age and need more or less support to achieve independence in their health and medical needs. However, as teenagers and their families begin thinking about and discussing the teenager’s unique experiences and wants and needs (See Chapter One, “Creating a Health and Medical Map”), they may also find it useful to assess the teenager’s independence in typical health and medical issues. Table 2.2 provides a checklist of typical health and medical skills and behaviors needed by adolescents as they seek more independence, a rating of their independence, and a rating of its desirability or need to be addressed in the IEP/transition planning process and/or with appropriate health and medical professionals. Parents and educators will probably want to individualize this checklist - adding, subtracting, or changing items based upon a specific teenager’s experiences, wants, and needs.

What is the Family’s Role in Encouraging Health and Medical Independence?

Parents and family members of adolescents with disabilities and/or special health care needs can play an important role in preparing their children for and connecting them to the adult health and medical care system. Table 2.3 offers suggestions for parents and other family members to consider.

Summary

By this point in the transition planning process, teenagers and their families have spent some time thinking about and planning for the unique health and medical skills and behaviors the teenager will need in order to be more independent at home, at school, and in the workplace. An individualized health and medical plan is beginning to emerge and is being addressed in the appropriate forum(s).

The next step is to think about how to pay for health and medical insurance coverage. Chapter Three will help teenagers and their families identify and plan for health and medical insurance financial options. Following this, Chapter Four will help them identify the specific services needed and to work with the professionals who will provide these services to them.
<table>
<thead>
<tr>
<th>SKILL OR BEHAVIOR</th>
<th>I do this independently.</th>
<th>I can do parts of this independently or some of the time, but I need practice or support.</th>
<th>I cannot do this at all or can only do this with support.</th>
<th>This is a skill or behavior that I would like to address in my IEP/ statement of transition services and/or with my health care professionals.</th>
</tr>
</thead>
<tbody>
<tr>
<td>I can describe my disability and/or health and medical condition.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>I can describe the implications of my disability and/or health and medical condition on my daily life and activities.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>I access/understand my health and medical records.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>I take responsibility for taking my own medications.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>I know how to use/read a thermometer.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>I take responsibility for doing my own medical treatments.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>I take responsibility for scheduling my own medical/dental appointments/treatments.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>I take responsibility for getting to/from my appointments.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>I take responsibility for getting my own prescriptions filled.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>I know my height, weight, birthdate, blood type, allergies, etc., and/or I carry the information in my wallet.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>

1 Table content/format suggested by materials developed by the PACER Center, 4826 Chicago Avenue South, Minneapolis, MN 55417
### Table 2.2 Checklist of Typical Adolescent Health and Medical Skills and Behaviors

<table>
<thead>
<tr>
<th>SKILL OR BEHAVIOR</th>
<th>I do this independently.</th>
<th>I can do parts of this independently or some of the time, but I need practice or support.</th>
<th>I cannot do this at all or can only do this with support.</th>
<th>This is a skill or behavior that I would like to address in my IEP/statement of transition services and/or with my health care professionals.</th>
</tr>
</thead>
<tbody>
<tr>
<td>I know emergency telephone number(s) and/or I carry the information in my wallet.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I know my medical coverage information and/or I carry the information in my wallet.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I can describe how my medical coverage works.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I can describe the roles of the medical professionals involved in my treatment.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I know/practice basic first aid and emergency procedures.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I know where/whom to call for additional health/medical information/materials (e.g., mental health, substance abuse concerns, genetic counseling, etc.).</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I take responsibility for my hygiene/self-care needs (e.g., shaving, menstrual care, etc.).</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I have identified a primary care physician for adult health/medical care.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I am comfortable talking to my medical/health care providers when I am alone.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I know how/am comfortable hiring/supervising a Personal Care Attendant (PCA).</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

1 Table content/format suggested by materials developed by the PACER Center, 4826 Chicago Avenue South, Minneapolis, MN 55417
<table>
<thead>
<tr>
<th>SKILL OR BEHAVIOR</th>
<th>I do this independently.</th>
<th>I can do parts of this independently or some of the time, but I need practice or support.</th>
<th>I cannot do this at all or can only do this with support.</th>
<th>This is a skill or behavior that I would like to address in my IEP/statement of transition services and/or with my health care professionals.</th>
</tr>
</thead>
<tbody>
<tr>
<td>I can do simple repairs on my wheelchair or other assistive equipment and/or I know where/whom to call.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I understand the employment-related mandates of the Americans with Disabilities Act (ADA) as they concern my disability and/or health/medical condition.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I understand/am comfortable talking to potential employers and/or post-secondary education programs about my disability and/or health/medical condition/support needs.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

1 Table content/format suggested by materials developed by the PACER Center, 4826 Chicago Avenue South, Minneapolis, MN 55417
Preparing for Independence at Home, at School, and in the Workplace

Table 2.3

<table>
<thead>
<tr>
<th>Family Suggestions for Encouraging Independence</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Begin discussion of health and medical issues with your adolescent by age 14, and continue discussions throughout adolescence and on into adulthood.</td>
</tr>
<tr>
<td>• Discuss with the pediatrician when and how information about your adolescent’s disability and/or special health care needs should be shared with the adolescent.</td>
</tr>
<tr>
<td>• Encourage the pediatrician to meet privately with the adolescent to discuss physical, emotional, social, intellectual, and nutritional changes.</td>
</tr>
<tr>
<td>• Share health and medical concerns with the adolescent’s IEP team (as appropriate).</td>
</tr>
<tr>
<td>• Talk with your adolescent about risk-taking behaviors, decision-making, self-regulation, and self-evaluation.</td>
</tr>
<tr>
<td>• (As appropriate) discuss need for arranging formal limits on medical and financial decisions and initiate legal process.</td>
</tr>
<tr>
<td>• With your adolescent, begin the development of a file containing his or her health and medical information.</td>
</tr>
<tr>
<td>• Encourage your adolescent to assume greater independence or to partially participate in scheduling appointments, asking questions of providers, choosing providers, managing medications or treatments, and managing files.</td>
</tr>
<tr>
<td>• Model appropriate health and medical behaviors yourself.</td>
</tr>
</tbody>
</table>
CHAPTER THREE

Paying for Health and Medical Care

Obtaining and maintaining insurance to cover health and medical services is a major concern for nearly all teenagers with disabilities and/or special health care needs and their families. It is a concern that must be addressed as part of the teenager’s formal transition planning. It is never too early to be aware of options and to begin discussing those that best meet the teenager and family’s needs, but discussion and exploration of health and medical care financing options must begin no later than when the teenager turns 17 years old.

Private Insurance

Private insurance is offered to many employees as part of their employee benefits package. In some cases, families will have private insurance and the policy will cover the health and medical needs of the family’s child with a disability. Some of these policies will maintain dependents with severe disabilities even after the child turns 18. Families with private insurance coverage must contact their employee benefits representative before their child turns 18 and consider the options available to them when their child does turn 18.

Depending upon the policy, unmarried adult children, with and without disabilities, who are 18 years and older may remain on the family’s policy until age 25 if they are enrolled full-time in a post-secondary education program. If an unmarried child age 18 or older does not continue in school, families have an opportunity to continue coverage on the child on the policy under COBRA coverage guidelines for a specified period of time. COBRA (Consolidated Omnibus Reconciliation Act, as amended) is a federal law covering companies with more than 20 employees, as well as state and local governments. Among its many provisions, COBRA allows
families to continue coverage by using their own funds to purchase the company’s policy to cover their adult unmarried child. An advantage of COBRA is that it allows continuous time-limited coverage for the child’s preexisting condition(s). A disadvantage is that the policy may be too costly for many families to consider. Another disadvantage is that the coverage is time-limited; COBRA coverage under these conditions will expire after a specified period of time. For detailed information on specific policies and/or COBRA coverage, teenagers and their families must contact their employee benefits representative.

**Medicaid**

For many families for whom private insurance is not an affordable option, Medicaid is an option. Across the United States, Medicaid provides health and medical coverage to many children with disabilities and/or special health care needs. Medicaid is also the primary health care option for many unemployed or underemployed adults with disabilities and/or special health care needs.

Medicaid is funded jointly by the federal and individual state governments. Each state-administered program provides federal and state tax-supported medical coverage for eligible residents with low incomes and limited resources. As a result, the Medicaid program differs from state to state, as well as changes within a state from time to time. In most states, including Louisiana, eligibility for SSI (Supplemental Security Income) automatically makes one eligible for Medicaid. In other states, applying for and being determined eligible for SSI and Medicaid require two different applications and processes.

Many families who have a child with disabilities and/or special health care needs will have Medicaid as their child’s primary form of health and medical insurance because of the family’s low income and limited resources. For those families who have too high of an income and/or too many resources to be eligible for Medicaid, it is important to know that, upon reaching age 18, many adults with disabilities will be eligible for Medicaid based on their own personal incomes and resources. Once a child reaches age 18, the family’s income and resources are no longer considered in determining the young adult’s eligibility for Medicaid.

**Helpful Hints**

The first and most important step that teenagers and their families must take is to become familiar with the health and medical insurance option(s) available to them. If they have private insurance, they must review their policies carefully, prepare a list of questions, and contact their insurance providers to obtain specific answers. To the extent possible, involving the teenager in this process is an excellent way to
build his or her knowledge and self-determination skills and behaviors.

If teenagers and their families have Medicaid or are anticipating a transition from private coverage to Medicaid, they must review available materials on Medicaid (See Appendix C for a listing of helpful health and medical resources.), prepare a list of questions, and contact the agency in their state that administers Medicaid services to obtain specific answers. In Louisiana, this office is located within the Louisiana Department of Health and Hospitals (225/342-5716, 225/342-5774, or 888/342-6207) or http://www.dhh.state.la.us/medicaid. Once again, to the extent possible, involving the teenager in this process is an excellent way to build his or her knowledge and self-determination skills and behaviors.

When teenagers and their families disagree with decisions made by their private insurance providers or Medicaid, they have a right to file a grievance. Specific procedures will vary across providers and must be followed, but in most cases, the key to success will depend upon:

(a) Knowing the policy and grievance procedures;
(b) Maintaining communication with the claims office and representatives. Ask for a toll-free telephone number to reduce telephone costs. Get to know and build rapport with your claims adjuster;
(c) Maintaining accurate records of dates, names, telephone correspondence, and copies of letters; and
(d) Asking for help from other families, trusted health and medical care providers, and, in some cases, legislators and other policy makers.

Summary

Obtaining and maintaining insurance to cover health and medical care is a major transition planning concern for teenagers with disabilities and/or special health care needs and their families. Understanding private insurance and Medicaid options requires time and perseverance. Some teenagers and their families may prefer to gather the necessary information and make decisions without involving professionals. Others may want and need assistance from educators, therapists, pediatric and adult health care providers, and other professionals. Whether it is addressed privately by teenagers and their families or by a team during the more formal transition planning process, it must begin before the teenager reaches age 18.

Availability of insurance is the foundation for the next step in the process. This step, choosing and working with health and medical care providers, is discussed in Chapter Four.
CHAPTER FOUR

Choosing and Working With Health and Medical Providers

Moving from the pediatric to the adult health and medical care system is an important task during the transition time period. This task can be very traumatic for most teenagers with disabilities and/or special health care needs and their families. In fact, studies indicate that many do not adequately plan for or make an effective transition. That is, they may not identify or use an adult provider until many years after leaving high school when they experience a health or medical difficulty or when they have already established independence at home, at school, and in the workplace. For teenagers with disabilities and/or special health care needs, going several years without health and medical care must not occur because they may develop life-threatening problems with little or no warning. Thus, proactive planning to ensure that teenagers and their families know how to choose and work with adult providers for regular health and medical care is an essential part of transition planning.

Overview of Health and Medical Providers and Specialists

The first decision teenagers and their families must make is to determine what adult services are needed. The first step in deciding what services are needed is to understand the difference between the many health and medical care providers potentially available to them as adults.

Regular and emergency health and medical care providers for adults might include physicians, nurses, therapists, pharmacists, equipment vendors, and/or medical supply companies. Throughout the transition planning years and on into adulthood, the needs of young adults will vary. Some young adults will need all of these services, whereas others only will need a few. Some young adults may need certain services less frequently once
they reach maturity. Others will benefit most from certain services when they make specific transitions and become more independent at home, at school, and in the workplace. But all teenagers and their families should be aware of the various roles these providers can play and should be prepared to choose and work with those that best meet their individual wants and needs.

Around age 18, but before age 21 or 22, all teenagers should transition from a pediatrician to a primary care physician or family practitioner. Similar to a pediatrician, this physician will provide regular health care, monitoring, and coordination of specialty services. The pediatrician, who is familiar with the teenager and family, can and should assist the teenager in making a smooth and successful transition by sharing records and reports, but also by helping the teenager and family to determine needed and desired adult services and to choose and work with adult providers.

If they have not already done so by this point, all young adults should also choose and begin to use other general health care providers to provide routine health care services. These providers should include a dentist and an ophthalmologist (eye doctor). Women should also schedule a routine gynecological exam every one to two years either with their primary care physician or family practitioner or with a gynecologist.

Many individuals with disabilities and/or special health care needs will also need to choose and use specialty care providers specific to their needs. One of the roles of the primary care physician or family practitioner is to guide the teenager and family in identifying wants and needs for specialty services. For example, a dietician, a neurologist, and/or an orthopedist, among others, may play critical roles in some transition-age young adults’ health and medical services.

The roles and services of the most common health and medical providers are described in Table 4.1. Information on additional providers is included in Appendix A, Glossary of Health and Medical Terms, at the end of this manual.
<table>
<thead>
<tr>
<th>HEALTH /MEDICAL PROVIDERS</th>
<th>ROLE</th>
<th>TYPICAL SERVICES</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family Practitioner</td>
<td>Physician or Nurse</td>
<td>Provides regular health/medical care through routine visits; monitors health status; gives immunizations and prescriptions for services (e.g., drugs, therapies, etc.) and coordinates care provided by specialists.</td>
</tr>
<tr>
<td>Dentist</td>
<td>Dentist</td>
<td>Provides regular check-ups and care for teeth, jaws, and mouth. A dental hygienist may clean teeth every six months or as recommended. The dentist may treat conditions or recommend specialists if more serious problems are identified, for example, an orthodontist or oral surgeon.</td>
</tr>
<tr>
<td>Dietician</td>
<td>Nutrition Counseling</td>
<td>Provides assistance with nutritional needs, menu planning, and eating disorders.</td>
</tr>
<tr>
<td>Gynecologist</td>
<td>Physician</td>
<td>Provides regular care for females (i.e., breast exams, pap smears, birth control measures, pregnancy, and prenatal care).</td>
</tr>
<tr>
<td>Neurologist</td>
<td>Physician</td>
<td>Monitors status of nervous system (i.e., nerves, spinal cord, and brain) and treats problems.</td>
</tr>
<tr>
<td>Neurosurgeon</td>
<td>Physician</td>
<td>Specializes in the operative treatment [surgery] of disorders involving the nervous system (i.e., nerves, spinal cord, and brain).</td>
</tr>
<tr>
<td>Occupational Therapist</td>
<td>Therapist</td>
<td>Provides evaluation and treatment of fine motor functions and ability to perform activities of daily living. Home, school, or center-based visits will be individually scheduled on a regular basis (e.g., 2-3 times a week initially and reduced to quarterly for follow-up monitoring and treatment).</td>
</tr>
<tr>
<td>Ophthalmologist</td>
<td>Physician</td>
<td>Monitors visual status and treats problems with structure, functions, and diseases of the eye. May prescribe and check eyeglasses, recommend and provide treatments, and/or perform surgery.</td>
</tr>
<tr>
<td>Orthopedist</td>
<td>Physician</td>
<td>Monitors mobility status and treats skeletal problems (e.g., prescribes braces, adaptive equipment, therapy, etc.).</td>
</tr>
<tr>
<td>Physical Therapist</td>
<td>Therapist</td>
<td>Provides evaluation and treatment of gross motor functions. Home, school or center-based visits will be individually scheduled on a regular basis (e.g., 2-3 times a week initially and reduced to quarterly for monitoring and follow-up).</td>
</tr>
<tr>
<td>Pulmonologist</td>
<td>Physician</td>
<td>Monitors status of lung and respiratory system and treats problems with breathing.</td>
</tr>
<tr>
<td>Urologist</td>
<td>Physician</td>
<td>Monitors status of urinary or urogenital systems (i.e., excretion and reproduction) and treats problems.</td>
</tr>
</tbody>
</table>

1 Please refer to the glossary at the end of this manual for information on additional providers.
Choosing and Working With Health and Medical Providers

Selecting Health and Medical Care Providers

Teenagers and their families have the right to select adult health and medical care providers from an array of providers typically limited only by those available within their private insurance plans or as Medicaid providers. Selecting health care providers is an important decision and, to the extent possible, involving the teenager in this process is an excellent way to build his or her knowledge and self-determination skills and behaviors.

Deciding what is important in choosing a provider is a very personal decision. Some teenagers and their families will place a high priority on a professional who is part of the teenager’s health insurance plan and/or who is permitted to practice at a specific hospital. Others will be concerned with recommendations from the pediatrician or primary care physician, experiences of other family members and friends, experiences of others with similar disabilities or health needs, or proximity to home.

Providers may be identified through recommendations of other health and medical care providers, recommendations of other families and friends, physician referral services, hospital referral services, the yellow pages of your local telephone directory, or the Internet. Providers may also be found by attending disability-related conferences and support groups, reading disability-specific newsletters, and by attending trade shows.

Selected providers should be able to handle all of the young adult’s wants and needs, as well as work closely with him or her, his or her family, and other professionals to prevent and solve problems, support home care plans, and ensure the highest standards of care. Once teenagers and their families have identified one or several potential providers from the array of potential providers, there are many additional things to think about before making a final choice. Table 4.2 presents a list of questions that teenagers and their families may want to consider as they begin thinking about choosing and working with adult health and medical care providers.
Table 4.2  Checklist for Choosing and Working with Health and Medical Care Providers

<table>
<thead>
<tr>
<th>QUESTIONS</th>
<th>COMMENTS</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.  Is the provider accredited, certified, or licensed?</td>
<td></td>
</tr>
<tr>
<td>What hospital(s) is the provider affiliated with? If they are accredited,</td>
<td></td>
</tr>
<tr>
<td>certified, or licensed, you have some assurance that they meet certain</td>
<td></td>
</tr>
<tr>
<td>standards. If your insurance is to pay for this service, typically only</td>
<td></td>
</tr>
<tr>
<td>accredited, certified, or licensed providers are reimbursable.</td>
<td></td>
</tr>
<tr>
<td>2.  Are personnel trained/experienced in care of individuals with chronic</td>
<td></td>
</tr>
<tr>
<td>illnesses or disabilities similar to yours?</td>
<td></td>
</tr>
<tr>
<td>Consider not just the health and medical provider, but also the office</td>
<td></td>
</tr>
<tr>
<td>and support personnel who may assist or be present when services are</td>
<td></td>
</tr>
<tr>
<td>being provided.</td>
<td></td>
</tr>
<tr>
<td>3.  How will untrained personnel be educated?</td>
<td></td>
</tr>
<tr>
<td>Are you expected to train individuals about specific disability</td>
<td></td>
</tr>
<tr>
<td>characteristics and needs or will problems be addressed as they are</td>
<td></td>
</tr>
<tr>
<td>identified through communications with experienced personnel, patients</td>
<td></td>
</tr>
<tr>
<td>or families, professional in-service training, library research, etc.?</td>
<td></td>
</tr>
<tr>
<td>4.  What services are provided?</td>
<td></td>
</tr>
<tr>
<td>Does this provider offer office visits, emergency care, and/or hospital</td>
<td></td>
</tr>
<tr>
<td>care? Can all your equipment and supply needs be met by this one provider?</td>
<td></td>
</tr>
<tr>
<td>Does a home health agency provide RN, LPN, home health aide, OT, PT,</td>
<td></td>
</tr>
<tr>
<td>speech, equipment, and/or supplies? Most young adults and families prefer</td>
<td></td>
</tr>
<tr>
<td>to deal with as few providers as possible, whereas others choose to use</td>
<td></td>
</tr>
<tr>
<td>more than one provider in order to get the least expensive services and</td>
<td></td>
</tr>
<tr>
<td>equipment. The latter option often takes more management, time, and effort.</td>
<td></td>
</tr>
<tr>
<td>5.  Is there flexibility in scheduling?</td>
<td></td>
</tr>
<tr>
<td>Is the provider’s schedule convenient to your schedule? Are other options</td>
<td></td>
</tr>
<tr>
<td>available?</td>
<td></td>
</tr>
<tr>
<td>QUESTIONS</td>
<td>COMMENTS</td>
</tr>
<tr>
<td>--------------------------------------------------------------------------</td>
<td>----------</td>
</tr>
<tr>
<td>6. What provisions can be made for coordination of care?</td>
<td></td>
</tr>
<tr>
<td>How will your existing records be obtained? How will your current</td>
<td></td>
</tr>
<tr>
<td>records be shared with other providers? You may be able to make</td>
<td></td>
</tr>
<tr>
<td>arrangements to have certain information shared on a regular basis or</td>
<td></td>
</tr>
<tr>
<td>you may choose to authorize these arrangements on an “as needed”</td>
<td></td>
</tr>
<tr>
<td>basis.</td>
<td></td>
</tr>
<tr>
<td>7. How dependable is coverage for regular and emergency</td>
<td></td>
</tr>
<tr>
<td>situations?</td>
<td></td>
</tr>
<tr>
<td>How is coverage handled at night, on weekends, or during the provider’s</td>
<td></td>
</tr>
<tr>
<td>vacations? What would you have to do? If you use life support equipment,</td>
<td></td>
</tr>
<tr>
<td>e.g., oxygen or ventilators, what does the vendor do in the event of an</td>
<td></td>
</tr>
<tr>
<td>equipment failure? Does the company provide a loaner while equipment</td>
<td></td>
</tr>
<tr>
<td>is being repaired? What hospital(s) do they serve?</td>
<td></td>
</tr>
<tr>
<td>8. Is the provider located in a convenient, accessible place?</td>
<td></td>
</tr>
<tr>
<td>Are the building and office accessible? Do you have transportation to</td>
<td></td>
</tr>
<tr>
<td>get the services or will they come to you?</td>
<td></td>
</tr>
<tr>
<td>9. How is the plan of care for each individual developed?</td>
<td></td>
</tr>
<tr>
<td>Who develops it? How much input can you have into your plan of care?</td>
<td></td>
</tr>
<tr>
<td>Look for consideration of your knowledge and experience, want</td>
<td></td>
</tr>
<tr>
<td>and needs, family situation and resources? If disagreements emerge,</td>
<td></td>
</tr>
<tr>
<td>how are they resolved?</td>
<td></td>
</tr>
<tr>
<td>10. What is the cost for the services and how will it be paid?</td>
<td></td>
</tr>
<tr>
<td>Are you expected to pay for services as they are provided or will your</td>
<td></td>
</tr>
<tr>
<td>insurance provider be billed? Your insurance company may limit your</td>
<td></td>
</tr>
<tr>
<td>choices; however, you should be knowledgeable and comfortable with the</td>
<td></td>
</tr>
<tr>
<td>process the provider uses.</td>
<td></td>
</tr>
<tr>
<td>QUESTIONS</td>
<td>COMMENTS</td>
</tr>
<tr>
<td>--------------------------------------------------------------------------</td>
<td>----------</td>
</tr>
<tr>
<td>11. Will they share references with you from other professionals,</td>
<td></td>
</tr>
<tr>
<td>agencies, patients, and/or other families?</td>
<td></td>
</tr>
<tr>
<td>The recommendations or comments of other individuals can give you</td>
<td></td>
</tr>
<tr>
<td>information about how the provider works with other professionals,</td>
<td></td>
</tr>
<tr>
<td>young adults with similar wants and needs, and other families.</td>
<td></td>
</tr>
<tr>
<td>12. What hospital is the provider affiliated with?</td>
<td></td>
</tr>
<tr>
<td>Are all required hospital facilities accessible? Are the hospital’s</td>
<td></td>
</tr>
<tr>
<td>policies family- and disability-friendly?</td>
<td></td>
</tr>
</tbody>
</table>
The questions in Table 4.2 are only a starting point for thinking about what teenagers and their families want and need in any health and medical care provider: physician, nurse, therapist, pharmacist, equipment vendor, and/or medical supply company. Young adults and their families will probably want to individualize these questions - adding, subtracting, or changing them based on their experiences, wants and needs. Once again, to the extent possible, involving the teenager in this process is an excellent way to build his or her knowledge and self-determination skills and behaviors.

Once teenagers and their families have identified the questions that are important to them, they are ready to begin the process of choosing a provider that they feel best meets their experiences, wants, and needs. Table 4.2 may now be used as an interview form to help make a final decision about a provider. The office manager of the practice or center where the identified provider works will be able to answer many of these questions, but young adults and their families may also want to get some of the answers in writing and/or confirm them through an interview with the potential provider before they make a final choice.

Managing Health and Medical Needs

For most adults, the decision to make an appointment with a doctor or other health and medical care provider is made only after considerable thought. Adults often think a long time about whether they really need to see a professional. Even when the signs and symptoms of illness or disease become too obvious to ignore, adults may still postpone the decision to seek medical attention. Their thoughts lead them to think about many different options. “Maybe I will feel better tomorrow.” or “Maybe I can just buy something at the drug store.” Even routine check-ups may be postponed for many reasons, for example, “I’ll have more time or money next month.”

Transition planning must teach and support young adults to proactively manage their health and medical needs to the greatest level of independence possible. Management includes organizing records, deciding when and why appointments are needed, making appointments, preparing for appointments, communicating with the provider, and following prescribed treatments and care. Table 4.3 provides a personal skills checklist for teenagers and their families to consider as teenagers begin to assume responsibility for managing all or part of their health and medical needs and care.
### ORGANIZE RECORDS

I organize and maintain important records, such as my medical history, immunizations, doctors' visits, health treatments, medications, and allergies.

I carry a brief record of my health and medical concerns with me. I know with whom it is appropriate to share this information and when it is appropriate to share it.

Other:

<table>
<thead>
<tr>
<th>Skill or Behavior</th>
<th>I do this independently.</th>
<th>I can do parts of this independently or some of the time, but I need practice or support.</th>
<th>I cannot do this at all or can only do this with support.</th>
<th>Is this a priority?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### DECIDE WHEN AND WHY APPOINTMENTS ARE NECESSARY

I know how often I should schedule routine check-ups with my primary physician.

I know how often I should schedule check-ups with specialists.

I recognize and can describe my own disability and/or health condition.

I recognize early signs and symptoms of disability or health problems.

I respond appropriately to these signs and symptoms by making appointments with appropriate provider(s).

Other:

<table>
<thead>
<tr>
<th>Skill or Behavior</th>
<th>I do this independently.</th>
<th>I can do parts of this independently or some of the time, but I need practice or support.</th>
<th>I cannot do this at all or can only do this with support.</th>
<th>Is this a priority?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

TABLE 4.3 Personal Skills Checklist: Managing Health and Medical Care Needs
### Make Appointments

<table>
<thead>
<tr>
<th>Skill or Behavior</th>
<th>I do this independently</th>
<th>I can do parts of this independently or some of the time, but I need practice or support</th>
<th>I cannot do this at all or can only do this with support</th>
<th>Is this a priority?</th>
</tr>
</thead>
<tbody>
<tr>
<td>I know whom to call, when to call, and how to call to make any necessary appointments.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>I can share all necessary medical information from my records.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>I can describe my signs and symptoms to the receptionist or nurse.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>I can make transportation arrangements.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>I can describe any special accommodations or needs.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>I can follow all pre-appointment requirements.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Other:</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>

### Prepare for Appointments

<table>
<thead>
<tr>
<th>Skill or Behavior</th>
<th>I do this independently</th>
<th>I can do parts of this independently or some of the time, but I need practice or support</th>
<th>I cannot do this at all or can only do this with support</th>
<th>Is this a priority?</th>
</tr>
</thead>
<tbody>
<tr>
<td>I can confirm transportation arrangements.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>I can confirm the date, time, location, and pre-appointment requirements.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>I can collect all of my records and medications and carry them to the appointment.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>I can make and bring a list of questions to ask the provider.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>I can identify someone to accompany me to the appointment if that would make me feel more comfortable.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Other:</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Skill or Behavior</td>
<td>I do this independently.</td>
<td>I can do parts of this independently or some of the time, but I need practice or support.</td>
<td>I cannot do this at all or can only do this with support.</td>
<td>Is this a priority?</td>
</tr>
<tr>
<td>---------------------------------------------------------------------------------</td>
<td>--------------------------</td>
<td>---------------------------------------------------------------------------------------------</td>
<td>-----------------------------------------------------------</td>
<td>-------------------</td>
</tr>
<tr>
<td>COMMUNICATE WITH PROVIDERS AND FOLLOW PRESCRIBED TREATMENTS AND CARE</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I can communicate my questions and concerns to the provider.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I can ask questions about prescribed tests, medications, side effects, and surgical procedures.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I can write down information about post-appointment needs.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I can follow any post-appointment procedures.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Organize records

Many teenagers with disabilities and/or health care needs can learn to independently organize important records of their medical history, immunizations, doctors’ visits, health treatments, medications, and allergies. Others will be able to organize and maintain their records with support from family members or other trusted adults.

Even teenagers who may not be able to demonstrate complete independence can still demonstrate a degree of independence by carrying a brief record of their individual health and medical concerns in their wallets or purses and knowing whom it is appropriate to share this information with and when it is appropriate to share the information. This record should include personal information (such as name, home address, emergency contact information, insurance information, etc.), blood type, medications, allergies, name and contact information for primary care provider, and any other emergency actions. Examples of emergency actions might include the need for an interpreter, need for food or drink, need for special transportation, etc.

Decide when appointments are necessary

Teenagers and their families must be encouraged to recognize when health and medical attention is needed. By understanding one’s disability and/or medical and health condition and by paying attention to signals from one’s body, one can learn both to recognize early signs and symptoms of illness and to identify optimal health time periods. For example, does the teenager sometimes have a runny nose or red eyes? What time of day does the teenager usually feel best - in the morning, afternoon, or evening? Teenagers can learn to recognize anything that is different about their health by giving themselves a daily health check:

1. Does your body temperature fluctuate?
2. Does your level of energy and activity vary?
3. Does your skin appearance vary? For example, is it sometimes red, pale, sweaty, or dry?
4. Does your mood and behavior vary? For example, do you sometimes feel angry or cry for unknown reasons?
5. Do your eating habits vary? For example, do you sometimes lack an appetite or are you sometimes extremely hungry?
6. Do you have any regularly occurring body aches and pains?
7. What are your typical bowel and urinary routines and conditions?
Decide why appointments are necessary

Routine check-ups are important for all young adults and some tests are recommended at certain periods in one’s life. In addition, chronic illnesses and certain health and medical conditions often require periodic laboratory tests and x-rays. By organizing their records and knowing themselves, young adults will be able to decide when an appointment might be necessary, what provider is most appropriate for them to see, and whether they need to visit their primary physician before seeking services from a specialist. When they contact the appropriate provider, they will be able to state why an appointment is necessary and, thus, receive appropriate services in a timely manner.

Make appointments

Files should include information on providers’ office hours, along with telephone numbers for before and after office hours. When calling for an appointment, young adults should be prepared to provide the following information:

(1) Is the requested appointment for a routine check-up or an emergency? If you are not certain, be prepared to describe, for example, when your symptoms began, how long they have lasted, the location and degree of pain you are experiencing, etc., so that the office may help you determine the urgency of the need for an appointment. Mention any allergies.

(2) Have your personal and medical information in front of you.

(3) Do you have any transportation or accessibility needs? For example, will you be using public transit and need the location of the nearest bus stop? Will you be using a special medical and health transportation service? As a result of transportation needs, will you need an appointment on a specific day of the week or before or after a specific time? Will you need assistance entering the building or provider’s office? Will you need any special accommodations in the office or during testing or laboratory procedures? For example, assistance transferring from a wheelchair to an examining table, assistance dressing and undressing, etc. Will you need an interpreter?
(4) Ask for and be prepared to follow pre-appointment requirements. For example, is there a need to fast or refrain from eating or drinking certain foods or liquids? Ask if there are any limitations or support needs your disability or condition might impose on any testing conditions. Mention any allergies. Write down any pre-appointment requirements.

(5) Describe your specific concern for this requested visit, not your medical history. Describe the signs and symptoms of illness you have noticed.

(6) Write down the name of the person you need to speak to if you have any additional questions before the day of the appointment.

(7) Ask if there is anything you need to bring with you to your appointment.

(8) If you would feel more comfortable being accompanied by a friend or family member, ask someone to accompany you to the appointment.

(9) If you cannot see the provider immediately and you feel your need is an emergency, seek permission to go to the emergency room or see an alternate provider.

Prepare for appointments

Preparing for an appointment requires several activities:

(1) Identify and confirm transportation arrangements.

(2) Confirm the date, time, and address of the appointment.

(3) Confirm the need for any special preparations (e.g., fasting, pre-appointment procedures, special clothing for examinations, etc.). Patients with more significant disabilities may benefit from an orientation visit to the provider’s office or role-playing unfamiliar examinations or procedures.

(4) If someone is accompanying you, confirm his or her participation.

(5) Make a written list of concerns, questions, symptoms, and signs you want to discuss with the provider.

(6) Collect all records (e.g., personal information, medications, copies of test results, names of other providers, etc.)

(7) Plan to arrive at the office a few minutes early; call ahead to confirm that the provider is running on schedule.
Communicate with providers and follow prescribed treatments and care

If the steps above have been followed, the patient will feel prepared and, thus, more relaxed. Patients should also follow any additional steps they want and need to feel relaxed and comfortable during their appointments. In addition:

(1) Wear comfortable clothing that is appropriate for the appointment. (e.g., sandals for a podiatrist’s appointment, loose shirtsleeves for blood tests, etc.).

(2) Ask the person accompanying you to stay with you during whatever portion of the appointment you desire.

(3) Describe the reason(s) for your visit and answer the provider’s questions honestly.

(4) Ask the providers questions, take notes, or ask the person accompanying you to take notes.

(5) Repeat the information given to you before you write it down.

(6) Verify follow-up needs (e.g., follow-up appointments, change in medications and/or diet, additional testing needs, symptoms to be aware of, etc.).

Helpful Hints

Working with health and medical providers may be stressful for young adults and their families, but, overall, it should be a positive experience. Patients have a right to give both positive and constructive feedback to providers about the health and medical services they receive. They may choose to do this verbally at the end of the visit by telling the provider how they felt about the services they received. They may choose to do this in writing by personalizing a follow-up letter to the provider after the visit describing how they felt about the services received. They may choose to identify themselves when providing this feedback or they may prefer to provide it anonymously. Appendix D provides a set of postcards developed by families that some young adults and their families have found useful in providing feedback to providers. (These postcards may be duplicated and/or revised without permission of the authors.)
Summary

Choosing and working with health and medical providers are important tasks in making the transition from the pediatric to the adult health and medical care. For young adults and their families, this process can be traumatic and, thus, may not be addressed until several years later when young adults may have developed life-threatening problems or already have established independence at work, school, or home. Proactive planning for choosing and working with providers for regular health and medical care is an essential part of formal transition planning and must be addressed during the teenage years. Chapter Five provides families and service providers with more specific information, guidelines, and suggested strategies for building the self-determination knowledge and skills of teenagers with disabilities and/or special health care needs.
Self-determination is the combination of beliefs, knowledge, and skills that enable a person to engage in goal-directed and independent behavior. Self-determined young adults review choices, make decisions, set goals, solve problems, evaluate themselves, and attain goals. They are aware of their preferences, their strengths, and their needs. They can motivate themselves and have positive attitudes about their abilities to attain their goals. Specific to health and medical care, self-determined young adults manage their health and medical care by engaging in the behaviors described in Chapter Four with as much independence as possible and with whatever supports they want and need.
Assessing Self-determination in Health and Medical Care

Building self-determination in adolescents begins with assessing their abilities, Table 4.3. This assessment should include a self-assessment by the young adult, as well as input from family members and professionals who know the young adult well. What can the teenager do independently? What can the teenager do with support? What will family members or other adults need to do for the teenager? What are the teenager’s preferences, wants, and needs? What are the family’s preferences, wants, and needs?

As was discussed in Chapter Two, developing independence is one of the primary tasks of adolescence. However, interdependency must also be considered. Most people, whether they have a disability or not, depend on other people. For example, adults routinely depend on family, friends, co-workers, bankers, babysitters, teachers, retail and grocery clerks, elected officials, and government workers. They also depend on assistive devices. For example, telephones, cars, buses, computers, eyeglasses, personal planners, newspapers, TV, radio, air conditioners, refrigerators, and so forth. Could most adults survive without these people and devices? Probably so, but most adults would agree that doing without them would greatly diminish their quality of life. These people and devices are typically referred to as natural supports. That is, supports that are available naturally to people in their homes, schools, workplaces, and larger community. The key to building independence among adults with disabilities and/or special health care needs is to find a balance between self-sufficiency and natural support systems made up of people and assistive devices. Thus, the next step is to use the needs identified in the assessment to identify and prioritize health and medical needs that might be addressed in the IEP/statement of transition services and/or pursued less formally by the teenager, his or her family, and/or health care providers.

Strategies for Developing Self-determination in Health and Medical Care

Once areas of need have been identified and prioritized, teenagers, their families, and their team members must decide whether the need is best addressed by: a) exposure to more practice and skill training; b) use of assistive devices; c) use of natural supports; or d) several of the above options. Table 5.1 provides some suggested strategies for systematically building the self-determination of teenagers with disabilities and/or special health care needs.
<table>
<thead>
<tr>
<th>SELF-DETERMINATION, BELIEFS, KNOWLEDGE, AND SKILLS</th>
<th>SUGGESTED STRATEGIES</th>
</tr>
</thead>
</table>
| **Make Decisions** | • Include teenager in choosing health and medical care providers (e.g., interviewing primary care provider, personal care attendants, etc.).  
• Include teenager in choosing schedules for treatments, medications, and procedures (e.g., after baseball season, during spring vacation, etc.).  
• Include teenager in reviewing treatment, medication, and procedural options.  
• Include teenager in choosing food, beverages, therapy, or exercise routines required by disability and/or special health care needs. |
| **Set Goals** | • Break complex health care routines into smaller tasks and guide teenager through assuming responsibility for one step at a time (e.g., assign responsibility for remembering and charting morning medications or after-school insulin testing, etc.).  
• Develop and encourage use of charts or cues as reminders (e.g., charts for the teenager to check when medication has been taken, etc.).  
• Include teenager in monitoring when prescriptions need to be refilled and in communicating with the pharmacist or other provider(s).  
• Include teenager in deciding what information to include in medical files and how to organize the files. |
| **Review Choices** | • Include teenager in setting and following schedules for increasing independence in following therapy and other home-based treatments.  
• Develop and encourage use of charts or cues as reminders (e.g., scripts to use when calling providers to make appointments, etc.) and provide specific reinforcement for gradual increases in independence (e.g., more privacy, more choices, etc.). |
| **Solve Problems** | • Discuss family concerns with teenager and identify options that allow teenager to increase independence while adhering to a required medical or health regimen (e.g., eating food with high sugar content on weekends, delaying medication by 1 hour during football practice, etc.). |
| **Self-Evaluate/Attain Goals** | • Encourage the teenager to discuss his or her progress with the provider in private, attending to success as well as ongoing problems.  
• Encourage teenager to share information on disability and/or special health care needs with other teenagers and to join support groups or Internet chat rooms. |
Summary

Helping young adults develop the beliefs, knowledge, and behaviors necessary to manage their own health and medical care is a critical component of self-determination preparation and overall transition planning for all teenagers with disabilities and/or special health care needs. Self-determined young adults assume responsibility for managing their own health and medical care with as much independence as possible and with as much support as wanted and needed.

Self-determined young adults manage their health care needs by reviewing choices, making decisions, setting goals, solving problems, evaluating themselves, and attaining their goals.
Disability occurs across our life span and is the consequence of physical impairments, mental impairments, or health care conditions, which may begin very early in life, occur as the result of injury, or develop later in life. Having a disability does not mean one cannot or should not live a healthy lifestyle. As we have seen in previous chapters, helping young adults with disabilities and/or special health care needs understand the causes and impacts of their conditions will help them determine their strengths, as well as their support needs and limitations. In addition, helping them define their disabilities and/or special health care needs in terms of the conditions’ internal and external impacts will help them determine strategies for minimizing their limitations and for managing their health and medical needs more independently. Young adults who have the self-determination beliefs, knowledge, and skills to understand their conditions and to engage in the behaviors described throughout this guide are well on their way to developing healthy lifestyle behaviors that will enhance their quality of life.

What is a Healthy Lifestyle?

Adults who adopt a healthy lifestyle have a quality of life characterized by good health, feeling good, being independent, having control, and pursuing happiness. The health of adults, and ultimately their quality of life, is critically linked to the behaviors they chose to adopt as adolescents. Adoption of healthy behaviors among teenagers is impacted not only by their specific conditions (i.e., internal impacts), but also by the social and cultural environments (i.e., external impacts) in which they reside. Quality of life is defined as an individual’s perception of his or her position in relation to his or her goals, expectations, and concerns. Improving one’s quality of life means
promoting opportunities to achieve independence, equality, participation, satisfaction, and economic self-sufficiency. Being able to manage one’s health and medical needs, as described throughout this guide, is a very important key to improving one’s health and, ultimately, one’s quality of life.

Basic Ingredients of a Healthy Lifestyle

Young adults with disabilities must become active partners with their families and health and medical care providers in adopting healthy lifestyles that build upon a holistic model and address the full spectrum of their lives. For example, a healthy lifestyle that includes good hygiene, regular exercise, and a careful diet will enhance employment opportunities and economic self-sufficiency. The purpose of this chapter is to summarize the ingredients of a healthy lifestyle for young adults with disabilities and/or special health care needs.

Hygiene

Basic hygiene practices that all adults should adopt on a daily basis include bathing, keeping hair and nails clean, and brushing one’s teeth. Managing these basic hygiene tasks may be more complex when a young adult has a disability and/or special health care condition. For example, some young adults will require assistance from other people (e.g., personal care attendants, family members, or residential services staff). Others will be able to attain a degree of independence through instruction or practice or through the use of assistive devices. For young adults who have difficulty bathing, there are many commercially-available devices that can make bathing easier, for example: grab bars, transfer seats, shower chairs, and handheld nozzles. For young adults who have difficulty with hair and nail care, a simple haircut and neatly-clipped nails can help them maintain a neat appearance. Good oral health is important to total health. There are many commercially-available devices that can make brushing and flossing teeth easier, for example: enlarged toothbrush handles, enlarged holders for floss, and electric toothbrushes.

Exercise

Nearly half of all American youth between 12 and 21 are not physically active on a regular basis. Recent studies, for example, note that: (a) more than a third do not participate in vigorous physical activity; (b) more than three-quarters do not participate in even moderate physical activity; (c) nearly half are not enrolled in
physical education classes; and (d) less than a third of students who are enrolled in physical education classes exercise for the recommended 20 minute time period. Among young adults with disabilities and/or special health care needs, studies have found that they are even less likely to engage in regular exercise than their peers without disabilities or special health care needs. They are also more likely to evidence feelings of low self-worth and to be assessed as less physically fit.

Being physically fit means balancing many areas including:

1. Cardiorespiratory endurance (aerobic fitness), which is the ability of the heart, lungs, and circulatory system to deliver oxygen and nutrients to all areas of one’s body;
2. Body composition (body fat), which is the percentage of body weight that is fat;
3. Muscle strength and endurance, which is the amount of work and the amount of time that your muscles are able to perform a certain activity before they tire; and
4. Flexibility, which is the ability to move one’s joints and stretch muscles through a range of motion.

Working in partnership with their health and medical providers, young adults with disabilities and/or special health care needs can adopt an exercise regimen that includes aerobic exercises to strengthen the cardiorespiratory systems and burn fat, strength-building exercises to build muscle strength and endurance, and stretching exercises to improve flexibility.

Some popular forms of aerobic exercise are running, cycling, swimming, walking, cross-country skiing, dancing, using gym equipment (such as a stair climber), and playing sports (such as volleyball or basketball). To build muscle strength and endurance, many people work with weights. Free weights or weight machines can be used to build both strength and endurance. Most exercise gyms and clubs employ people to help beginners learn to use weights safely and properly. Callisthenic exercises, such as push-ups, pull-ups, and sit-ups, also build muscle strength and endurance. Stretching and deep breathing can be done to increase flexibility and relaxation. Activities such as yoga and martial arts will also help to improve flexibility and concentration. While all of these activities can be adapted to accommodate special needs and/or supports, it is always a good idea for teenagers with disabilities and/or special health care needs to check with their health and medical providers before beginning or expanding exercise regimens.
In addition to addressing any disability-related supports and/or special health care needs when developing an exercise program, consider the individual’s personal preferences. By considering these factors, it will increase the likelihood that the program will be both safe and enjoyable and that it will develop into a significant part of the young adult’s weekly routine. A sample exercise program is presented in Figure 6.1. Remember, this is just a sample. Each exercise program should be individualized to suit the teenager’s preferences, wants, needs, and supports. By selecting activities that they enjoy and by gradually building up to the ideal programs individually designed for them, teenagers with disabilities and/or special health care needs can incorporate a life-long routine to promote a healthy lifestyle.

When designing individualized exercise programs, remember that not all exercise programs require expensive tools, weights, or other equipment. There are a number of inexpensive commercially-available, household, and homemade options that can be used to enhance exercise. Items such as cans of food, books, Frisbees, bean bags, rolls of coins, and bags of rice can be used safely and effectively as weights. Furthermore, teenagers do not have to join an exercise gym or take a class to learn how to exercise properly. There are many illustrated books and videotapes that can assist novices in getting started with exercise programs, as well as supply catalogs that describe assistive equipment and devices that have been designed for persons with limited mobility or limited upper/lower body movement. Finally, many communities offer free or inexpensive leagues, teams, or clubs for sports, such as soccer, volleyball, and basketball.

It is most important to work in partnership with one’s health and medical providers before designing or beginning any exercise program. In addition, consider these guidelines:

1. Keep the exercise program simple;
2. Set a goal and write it on an index card or in a log book that is in a clearly visible location and can be viewed often;
3. Make an appointment with yourself for exercise and keep it or reschedule it as you would any appointment;
4. Start slow and gradually increase time and intensity of program; and
5. Do approved exercises that you enjoy so that workouts are both safe and fun.
### Figure 6.1 Sample Exercise Program

**Weekly Goal:** Do aerobic exercise three days; complete strength training two days.

<table>
<thead>
<tr>
<th>Day</th>
<th>Monday</th>
<th>Tuesday</th>
<th>Wednesday</th>
<th>Thursday</th>
<th>Friday</th>
<th>Saturday</th>
<th>Sunday</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aerobic Exercise:</td>
<td>30 minutes-brisk walk</td>
<td>30 minutes-swimming</td>
<td>45 minutes-cycling</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Flexibility:</td>
<td>stretch</td>
<td>60 minutes-yoga class</td>
<td>stretch</td>
<td>60 minutes-yoga class</td>
<td>stretch</td>
<td>stretch</td>
<td>stretch</td>
</tr>
<tr>
<td>Strength Training:</td>
<td></td>
<td></td>
<td></td>
<td>15 minutes-lower body only</td>
<td></td>
<td>15 minutes-upper body only</td>
<td></td>
</tr>
</tbody>
</table>

**Goal for next week:** Increase aerobic exercise to four days; increase flexibility training in yoga class to three days.
Diet

Along with good hygiene and exercise, living a healthy lifestyle includes adopting good dietary habits. As the adage states, “You are what you eat”. Healthy eating has its rewards: reduced risk for many diseases; decreased chance of obesity; increased energy; increased longevity; and an improved sense of being. The USDA (United States Drug Administration) endorses a food pyramid. This pyramid, seen in Figure 6.2, suggests a diet that is rich in fruits, vegetables, breads, and grains and that limits fats, sweets, and oils.

Obesity, combined with a higher than recommended intake of fats, increases one’s risk for heart disease, high blood pressure, stroke, diabetes, and colon cancer. Working in partnership with your health and medical providers, consider these general guidelines:

- Eat at least five servings of fruits and vegetables every day. A serving is ½ cup of chopped, cooked, or canned fruits or vegetables, ¾ cup of fruit or vegetable juice, or 1 medium piece of fruit. Fruits and vegetables can be included in meals and eaten as snacks throughout the day. Many fruits make excellent, healthy desserts as well.
- Drink a sufficient amount of water each day. Nutritionists suggest that a person drink at least eight glasses of water each day. Replacing sodas and other nutritionally-empty drinks with water will help meet this daily requirement.
- Eat more whole-grain, high-fiber foods. An easy way to get more whole-grain foods in your diet is to replace white breads with whole-grain breads and to eat a whole-grain breakfast cereal that is high in fiber. Make sure to read nutritional labels to ensure that the food is actually made with whole grains.
- Include some low-fat and fat-free foods in your diet to reduce your fat intake. Some reduced-fat yogurts and cheeses taste just as good as the full-fat product and are a good way to transition to lower-fat foods.
- If possible, limit your intake of red meats and replace them with other proteins such as poultry, fish, and beans. Red meat can be a part of a healthy, balanced diet, but it must be consumed in moderation.
- Eat smaller portions of a greater variety of foods. Smaller portions will allow you to include all recommended foods without eating too much. The reduced-portion sizes will help balance the recommended number of servings for each of the food groups.
- Make dietary changes gradually and allow your body to adjust to the new foods and the different portion sizes.
Figure 6.2

Food Guide Pyramid

A Guide to Daily Food Choices

- **Fats, Oils, & Sweets**
  - USE SPARINGLY

- **Milk, Yogurt, & Cheese Group**
  - 2-3 Servings

- **Vegetable Group**
  - 3-5 Servings

- **Meat, Poultry, Fish, Dry Beans, Eggs, & Nuts Group**
  - 2-3 Servings

- **Fruit Group**
  - 2-4 Servings

- **Bread, Cereal, Rice, & Pasta Group**
  - 6-11 Servings

**KEY**
- □ Fat (naturally occurring and added)
- □ Sugars (added)

These symbols show that fat and added sugars come mostly from fats, oils, and sweets, but can be part of or added to foods from the other food groups as well.

Use the Food Guide Pyramid to help you eat better every day...the Dietary Guidelines way. Start with plenty of Breads, Cereals, Rice, and Pasta; Vegetables; and Fruits. Add two to three servings from the Milk group and two to three servings from the Meat group.

Each of these food groups provides some, but not all, of the nutrients you need. No one food group is more important than another — for good health you need them all. Go easy on fats, oils, and sweets, the foods in the small tip of the Pyramid.

SOURCE: U.S. Department of Agriculture/U.S. Department of Health and Human Services

To order a copy of “The Food Guide Pyramid” booklet, send a $1.00 check or money order made out to the Superintendent of Documents to: Consumer Information Center, Department 159-Y, Pueblo, Colorado 81009.

U.S. Department of Agriculture, Human Nutrition Information Service, August 1982, Leaflet No. 572
Sexuality

Humans are sexual beings, regardless of the presence of disabilities and/or special health care needs. The transition from childhood to adolescence and adulthood involves deeper, more personal relationships with other persons. Sexual feelings and relationships are a natural part of this transition for all adolescents. It is important to remember that, despite physical, sensory, cognitive, or health-related disabilities, young adults have sexual feelings, needs, and identities. Families and service providers must strive to view the sexuality of young adults in the total context of human relationships and to help them develop healthy and fulfilling adult relationships.

The transition years bring many questions about and opportunities to discuss sexual feelings, relationships, sexual exploitation and abuse, safe sex, and other issues. Lack of information among young adults may contribute to an inability to distinguish between appropriate public and private behaviors, unwanted pregnancy, and an increased risk of contracting sexually-transmitted diseases.

An essential aspect of a safe sexual relationship is contraceptive use. The use of contraceptives can protect the young adult from unwanted or unplanned pregnancies. Some contraceptive methods also protect against sexually-transmitted diseases.

There are many different types of contraceptive methods. Common contraceptives include: condoms; birth control pills; contraceptive shots; IUDs; diaphragms; spermicidal creams, foams, and jellies; and permanent sterilization. All of these methods provide a varying degree of protection against pregnancy. However, only the proper use of condoms provides protection against sexually-transmitted diseases such as AIDS, chlamydia, gonorrhea, and syphilis. Decisions about the use of contraceptives are best made by the young adult in conjunction with a trusted health care provider. Together, they can help decide what contraceptive method, if any, is most appropriate for the young adult.

Lack of opportunity to take part in social activities with same-age peers and segregated educational and residential settings can contribute to the development of socially-inappropriate behaviors. The young adult and his or her family should make a special effort to identify interesting, preferred, and accessible social activities in the community. An important part of the transition process involves developing adult relationships with peers in the community. Studies show that young adults with disabilities and/or special health care needs are at a greater risk
than their peers of being sexually exploited or abused. Thus, it is essential that families and service providers share specific information about appropriate and inappropriate behaviors, as well as providing opportunities for open discussions of these issues. An important part of the transition to adulthood involves gaining a mature identity of oneself as an adult. Responsible, mature sexuality can be an important aspect of this new adult identity. Families and service providers can support this development by encouraging and providing appropriate experiences that can help ensure that young adults become healthy adults.

**Mental Health**

Mental health is a state of successful mental functioning, resulting in productive activities, fulfilling relationships, and an ability to change and cope with disappointment and hardships. Mental health is essential to personal well-being, family and interpersonal relationships, one’s contributions to society, and overall quality of life. Good mental health in young adults relates to:

1. self-realization, which is an awareness of self and one’s ability to reach goals;
2. self-esteem, which is the way one thinks about oneself; and
3. the ability to interact effectively with family, school, and community.

Mental health problems appear in families of all backgrounds. However, problems are more prevalent in adolescents and young adults with disabilities, those with family histories of mental health problems and addictive disorders, those who experience multi-generational poverty, and those who experience caregiver separation, abuse, or neglect. Mental health problems can be characterized as one of two types: (1) mental health problems, which refer to the range of all diagnosable emotional, behavioral, and mental disorders (affecting one in every five young persons) and (2) serious emotional disturbances, which refer to the above disorders when they severely disrupt daily functioning in home, school, or community (affecting one in 20 young persons).

The three most common mental health problems found in adolescents are Attention Deficit Hyperactivity Disorder (ADHD), depression and suicide, and eating disorders. While these problems vary tremendously in characteristics and treatment, their impact on young adults and their families are similar. It is estimated that two-thirds of adolescents with mental health problems are not getting the help they need.
While ADHD is often diagnosed in childhood, it is becoming more frequently recognized for the first time in adolescents and adults. Young adults with ADHD may exhibit some of the following signs and symptoms:

- Restlessness, fidgeting, and inability to remain seated for extended periods of time;
- Easily distracted by extraneous stimuli;
- Difficulty waiting (e.g., waiting in line);
- May have trouble “filtering” thoughts or may blurt out thoughts and answers inappropriately;
- Difficulty following directions and instructions;
- Trouble following through on intentions and difficulty completing tasks; and
- Difficulty organizing self and environment (i.e., losing things, forgetting appointments).

The presence of several of these signs or symptoms may indicate that a physician familiar with the diagnosis and treatment of ADHD should do further testing of the affected individual.

Another mental health problem that is, unfortunately, common in young adults is depression. Some warning signs of depression include:

- Feeling sad, blue, or unhappy;
- Feeling tired and unable to concentrate;
- Feeling uneasy, restless, or irritable;
- Sleeping too little or too much;
- Eating too little or too much;
- Lack of interest in activities that used to be enjoyable;
- Feelings of inadequacy and failure; and
- Feelings of hopelessness.

Almost everyone has experienced some of these feelings at one time or another in their lives. However, if several of these symptoms have been present for extended periods of time (for example, for more than two weeks), then further evaluation should be done by a psychiatrist familiar with adolescent issues.

In its extreme form, depression can lead to suicide. Suicide is the third leading
cause of death among teenagers. Any young adult who is depressed is at greater risk of contemplating and/or attempting suicide. In addition to the above listed symptoms for depression, some signs that a young person might be considering suicide are:

- Loss of interest in friends, activities, and school;
- Giving belongings away;
- Talking about suicide as an option to ending problems;
- Sudden change(s) in mood; and
- Use of drugs and/or alcohol.

Any mention of suicide should be taken seriously. A threat of suicide may indicate that the young person needs help dealing with emotions and problems that are too difficult to deal with alone.

Common eating disorders include anorexia nervosa, bulimia nervosa, and compulsive overeating. All are characterized by extreme behaviors, attitudes, and emotions surrounding weight and food issues. Eating disorders can be life-threatening, if not properly diagnosed and controlled. In general, people suffering from anorexia nervosa lose excessive weight by self-starvation. Symptoms of anorexia nervosa include:

- Refusal to maintain body weight at or above a minimally normal weight for height, body type, age, and activity level;
- Intense fear of weight gain and being “fat”;
- Feeling “fat” or overweight despite extreme weight loss; and
- Cessation of menstrual periods.

Bulimia nervosa is characterized by a compulsive cycle of binge eating followed by purging of the food through vomiting, laxative abuse, and/or extreme over-exercising. Some symptoms of bulimia are:

- Repeated secretive episodes of bingeing and purging;
- Feeling out of control during a binge and eating beyond the point of comfortable fullness;
- Purging after a binge, often by self-induced vomiting, abuse of laxatives or diet pills, or excessive exercising;
- Frequent and/or excessive dieting; and
- Extreme concern with body weight and shape.
Compulsive overeating is characterized by periods of uncontrolled, impulsive, and/or continuous eating beyond the point of fullness. Some symptoms of compulsive overeating are:

- Repeated periods of uncontrolled eating beyond the point of comfortable fullness;
- Feeling out of control during a period of binge eating; and
- Feelings of shame and self-hatred, especially in regard to food and body weight.

Young adults who feel that they may be suffering from an eating disorder should seek the help of their physicians and their families. Eating disorders can be life-threatening and are difficult to overcome without professional help and/or family support.

Adolescents with mental health problems need special attention in order to succeed. Early help may improve the problem and, more importantly, prevent it from worsening. Each of these adolescent mental health issues must be viewed in the context of internal and external impacts: the specific disability and/or health care condition, developmental factors, and social environments, including family and peer groups.

Appropriate services include both psycho-social and pharmacological treatments. These services must be family-focused, culturally-competent, accessible, and of high quality. Psycho-social services include a range of treatments that may be provided as outpatient services, partial hospitalization or day treatment, residential services, or inpatient. Pharmacological services include an array of medications that either increase or decrease the supply of various chemicals in the brain. Psycho-social and pharmacological services may be provided singly or in combination.

Every young adult, especially those experiencing change or transition, is at risk for increased life stress, changes in self-esteem, and alcohol or drug misuse. Young adults should remain aware of these issues as they are working to create independent, healthy lifestyles for themselves. Young adults should take time to incorporate opportunities for fun and relaxation into their daily lives. Families of young adults should also become familiar with these issues and should provide opportunities for open discussion of these topics and others.
Summary

When adults adopt behaviors associated with healthy lifestyles, they are more likely to experience good health, independence, control, and happiness in their daily lives. Their overall quality of life is enhanced. The goal of transition planning as it pertains to health and medical issues is to assist young adults with disabilities and/or special health care needs in adopting healthy lifestyles. To accomplish this goal, transition planning must provide all teenagers with the knowledge, skills, and experiences necessary to pursue good hygiene, exercise, good dietary habits, and to address sexual and mental health wants and needs.
Appendix A

Glossary of Health and Medical Terms

**Abuse:** Physical, verbal, or emotional attack.

**Adapted Physical Education:** Alternative physical education for an individual with disabilities who, for whatever reason, may not safely or successfully engage in unrestricted participation in the vigorous activities of the regular physical education program on a full-time basis. Physical education refers to the development of physical and motor fitness, fundamental motor skills and patterns, and skills in aquatics, dance, individual and group games, and sports.

**Adaptive Equipment:** A modified everyday or specialized device or instrument that assists an individual in independent functioning, e.g., a computer switch, shower grab bar, telephone with loud ringer and/or large numbers, walker, wheel chair ramp, etc. See also: **Assistive Technology**.

**AIDS:** Acquired Immunodeficiency Syndrome (AIDS) is the most serious and final stage of an HIV infection, when an individual has one or more opportunistic infections or cancers. The term is used to denote the collection of illnesses that are caused by HIV infection. See also: **HIV**.

**Arthritis Specialist:** See **Rheumatologist**.

**Assessment:** Refers to the actual gathering of subjective and objective data, including information from physician(s) and other health and medical care providers, individuals with disabilities and/or special health care needs, and home caregiver(s) in order to make a diagnosis or treatment decision.

**Assistive Technology:** Refers to the use of science and technical equipment to assist an individual in more independent functioning, e.g., a hearing aid, a computer switch, environmental controls, etc. They can range from low-tech to high-tech, depending on the presenting needs and circumstances. See also: **Adaptive Equipment**.
**Audiologist:** Professional who provides diagnosis, evaluation, and treatment of hearing impairments. Many audiologists also fit and dispense hearing aids.

**Auditory Evoked Response [AER]:** A specialized type of hearing test that measures the electrical response of the brain to a standard sound; also called a BAER [Brainstem Auditory Evoked Response] hearing test.

**Augmentative Communication Device:** Refers to any technology which adds to one's ability to receive and express information, e.g., communication board, hearing aid, computer software, TDDs, etc.

**Blind:** Visual impairment so severe that it cannot be corrected to a level that enables functional sight for daily activities.

**Body composition:** (body fat): the percentage of body weight that is fat. Overweight people have more body fat in relation to the amount of bone and muscle in their bodies than do people who weigh the amount recommended for their height, age, and sex. Having high body fat increases the risk of diabetes, high blood pressure, and heart attacks.

**Cardiologist:** Physician who specializes in the diagnosis and treatment of disorders involving the heart.

**Cardiorespiratory endurance:** (aerobic fitness): ability of heart, lungs, and circulatory system to deliver oxygen and nutrients to all areas of the body. When an individual is not physically fit, the heart and lungs have to work extra hard to get the body the oxygen it needs during physical activity.

**Cerebral Vascular Accident [CVA]:** A stroke where there is damage to brain tissues because of a problem in a brain vessel. There may be a tear and bleeding into the brain (hemorrhage) or blockage of the blood vessel.

**Chiropractor:** A practitioner who provides care based on the belief that an individual's state of health is determined by the condition of the nervous system. Treatment commonly involves manipulation of the spinal column.

**Chronic or Degenerative Neurological and/or Orthopedic Condition:** Disease or illness of long duration showing little or slow progress or one with deterioration of condition pertaining to the brain, spinal cord, nerves and/or skeleton, muscles or joints, e.g., Cerebral Palsy, Muscular Dystrophy, etc.

**Congenital:** A condition that is present at, or before, birth although it may not be detected until later. It may be genetic, environmental, or caused by a combination of factors (multifactorial).
Congestive Heart Failure: A condition where there is an abnormal accumulation of fluid in the body due to heart problems.

Contracture: A joint abnormally fixed in a flexed position.

Convulsion: A sudden, violent, involuntary contraction of a group of muscles by a sudden and unusual discharge of electrical energy to the brain. A convulsion is sometimes referred to as a seizure, a 'spasm', or, (inappropriately) as a 'fit'. A convulsion may be tonic (muscle stiffening), conic (rapid muscle contraction and relaxation), focal, unilateral, or bilateral.

Counselor: An individual who provides advice or guidance, e.g., psychologist, psychiatric nurse practitioner, psychiatrist, social worker.

Deaf: Hearing impairment so severe that the individual’s hearing with amplified sound is not functional for communication purposes.

Deaf-blind: Concomitant hearing and visual impairments, the combination of which causes severe communication and other developmental and educational problems.

Dental Hygienist: A practitioner who is trained to provide regular oral health and tooth care under the supervision of a dentist and to provide education related to the teeth.

Dentist: A practitioner who is trained to provide regular check-ups and care of the teeth, gums, and underlying structures.

Dermatologist: Physician who specializes in the diagnosis and treatment of disorders involving the skin.

Developmental Delay: A diagnosis that is applied when developmental milestones are not reached during normal or expected age ranges in one or more of the following areas: cognitive, physical, language and speech, psychosocial, or self-help skills. A developmental delay identified in early childhood may or may not result in a later disability.

Disability: Congenital or acquired mental/physical condition that interferes with normal development and/or functioning of the body and limits one’s ability to be self-sufficient in society.

Doctor: Physician.

Drug Store: A place where prescription and non-prescription [across the counter] medications can be purchased. Prescription medications must be ordered by a licensed physician and dispensed by a pharmacist. The physician may order the medication over the telephone or in writing.
**Eating Disorder:** A condition that is characterized by extreme emotions, attitudes, and behaviors in regards to food and weight. Eating disorders include anorexia nervosa, bulimia nervosa, and compulsive overeating and can be life-threatening.

**Endocrinologist:** Physician who specializes in the diagnosis and treatment of disorders involving the glands that produce hormones, e.g., pituitary, adrenal, thyroid, pancreas.

**ENT:** Refers to the ears, nose, and throat. An ENT specialist is a physician who provides diagnosis and treatment of health problems related to the ears, nose, and throat. Also called an otolaryngologist.

**Family Practitioner:** Physician who provides diagnosis and treatment of health problems for individuals regardless of age or sex. A family practice physician may have additional training, beyond medical school, in internal medicine, pediatrics, surgery, psychiatry, and/or obstetrics and gynecology.

**Fine Motor:** Refers to coordination of the small muscles of the body, especially those of the hand and for activities of daily living, e.g., dressing.

**Flexibility:** The ability to move joints and stretch muscles through a full range of motion. A person with poor flexibility is more likely to get hurt during physical activity.

**Gastroenterologist:** Physician who specializes in the diagnosis and treatment of disorders involving the stomach and intestines.

**Genetic Disorder:** A condition caused by an abnormality in the structure of an individual’s genes. It may be inherited or the abnormality may be unique to that family member.

**Gross Motor:** Refers to coordination of the large muscles needed to perform activities of a daily living, e.g., moving arms and legs, running, standing, walking.

**Gynecologist:** Physician who specializes in the diagnosis and treatment of female health and disorders, especially those involving the reproductive tract.

**Hearing Impaired:** Limitation in the sense of hearing.

**Hematologist:** Physician who specializes in the diagnosis and treatment of disorders involving the blood and blood-forming organs.

**Hemiparesis:** Condition in which there is weakness of one side of the body.

**Hemiplegia:** Condition in which there is a loss of sensation or movement (paralysis) of one side of the body.
HIV: Human Immunodeficiency Virus (HIV) is a virus that interferes with the human defense mechanisms against disease and infection. It is transmitted by contact with infected blood or through sexual or intimate contact with an infected person. There is no cure for HIV at this time. See also: AIDS.

Homeopathist: Physician who provides care based on the belief that small doses of medicine can reduce the symptoms of a disease that large doses can cause.

Incontinence: The inability to control bladder or bowel elimination.

Infection Control: Procedures to limit the spread of disease.

Internist: Physician who specializes in the diagnosis and treatment of disorders involving the internal organs, e.g., spleen, intestines, etc.

Mental Health: Refers to the state of mind in which an individual is able to adapt, cope, and adjust to the stresses of everyday life.

Midline: Toward or in the middle, e.g., the navel is at the midline of the abdomen.

Mobility: Physical movement. See Orientation and Mobility.

Morbidity: The condition of being diseased. In public health, morbidity statistics are the ratio of sick to well persons in a community.

Muscle Strength and Endurance: The amount of work and the amount of time that your muscles are able to do a certain activity before they get tired, such as when lifting heavy objects or performing in-line skating.

Nephrologist: Physician who specializes in the diagnosis and treatment of disorders involving the kidneys.

Neurologist: Physician who specializes in the diagnosis and treatment of disorders involving the nervous system, that is, the nerves, spinal cord, brain.

Neuromuscular Disorders: Diseases that affect the nerves or muscles. Neuromuscular disorders affect the way the nervous system sends messages and/or the musculoskeletal system responds to these messages. Specific disorders which can affect motor development during infancy and early childhood include arthrogryposis, Duchenne’s muscular dystrophy, and infantile muscular atrophy. Intelligence ranges from normal to mentally retarded. There is no known effective treatment for the majority of these disorders at this time.
**Neurosurgeon:** Physician who specializes in the operative treatment of disorders involving the nervous system, that is, the nerves, spinal cord, brain.

**Nurse Practitioner [NP]:** A registered nurse with advanced education and training in a specialized area. An NP may provide primary health care to well individuals or those with chronic health conditions or a disability independently or in collaboration with physicians.

**Obstetrician:** Physician who specializes in pregnancy and childbirth.

**Occupational Therapist [OT]:** A professional trained in the process of the fine motor functioning and development. An OT focuses on the person's self-help skills and the person's ability to function in the environment. OTs also assess the person's need for adaptive equipment that can make motor movement easier.

**Oncologist:** Physician who specializes in the diagnosis and treatment of disorders involving cancer.

**Ophthalmologist:** Physician who specializes in the diagnosis and treatment of disorders involving the eye.

**Optician:** A professional who fits, prepares, and dispenses prescription eyeglasses and contact lenses.

**Optometrist:** A professional who provides treatment of the functional aspects of vision and the eye.

**Orientation and Mobility:** Services provided to blind or visually impaired persons by a trained, certified professional to enable them to systematically orient and move safely within their school, home, and community environments.

**Orthopedist:** Physician who specializes in the diagnosis and treatment of disorders involving the mobility system, including bones, joints, muscles, and related tissues.

**Orthotist:** An individual who designs, makes, and fits braces or other orthopedic devices prescribed by a physician.

**OSHA:** The Occupational Safety and Health Administration (OSHA), a part of the United States Department of Labor, which establishes regulations regarding safety and health in the workplace.

**Osteomalacia:** A condition of the bone characterized by a loss of calcification of the matrix, resulting in softening of the bone, accompanied by weakness, fracture, pain, loss of weight, and loss of appetite.
**Osteoporosis:**  Loss of bone density resulting in weakening and honeycomb-like appearance of the bone in x-rays. This can be a result of immobility, lack of calcium, or long-term anticonvulsant therapy.

**Osteopath:**  Physician who diagnoses and treats structural problems using manipulation, as well as the more traditional medical approaches including drugs, surgery, and radiation.

**Otolaryngology:**  Physician who specializes in the diagnosis and treatment of disorders involving the ears, nose, and throat.

**Otologist:**  Physician who specializes in the diagnosis and treatment of disorders involving the ear.

**Paralysis:**  Loss of motor function and/or sensation. A term usually used with anatomical words to describe location of problems, e.g., right arm paralysis.

**Paraparesis:**  Partial paralysis.

**Paraplegia:**  Paralysis in the lower extremities.

**Prenatal:**  Refers to the period around birth, usually 28 weeks gestation to 28 days to life.

**Peristalsis:**  The coordinated, rhythmic contraction of smooth muscle that moves food through the digestive tract.

**Personal Care Attendant [PCA]:**  A person who provides an individualized plan of support and services to a person with a disability and/or health care condition at home and/or in the community.

**Pharmacist:**  A professional trained in preparing and dispensing drugs or medications.

**Physiatrist:**  Physician who specializes in physical medicine and rehabilitation.

**Physical Therapist [PT]:**  Professional concerned mainly with the assessment and development of gross motor function. The focus is on the person's neuro-skeletal-muscular function and also assessment of the person's cardiopulmonary function and degree of general fitness. PTs are able to design adaptive equipment for positioning and mobility that can help the person to get maximum benefit from his/her environment.

**Physician:**  A professional who has earned a degree as a Doctor of Medicine.
Plastic Surgeon: Physician who specializes in the operative correction of a structural or cosmetic problem, e.g., cleft palate repair, nose alteration, etc.

Podiatrist: A health professional who specializes in the diagnosis and treatment of disorders involving the feet.

Pressure Relief: Refers to strategies which decrease the effects of weight on the skin (e.g., decubitus ulcers), including such things as changing position so that the weight of the body is moved from the hip bones to the sacrum and back, pressure relief exercises, gel pads, or alternating pressure cushions.

Pressure Sore or Ulcers: Skin breakdown caused by pressure. Also called bedsore or decubitus ulcer.

Primary Health Care Provider: A professional nurse or physician who provides health promotion, health screening, and basic health care.

Procedure: A set of “how to” action steps for performing an activity or task.

Prone: Lying on the stomach with the face down.

Psychiatric Disturbance: A disorder of thought, behavior, or emotion that can affect the ability to learn and grow.

Psychiatrist: Physician who specializes in the diagnosis and treatment of disorders involving mental, behavioral, and emotional processes.

Psychologist: A professional who provides evaluation and treatment/counseling to individuals with mental and emotional disorders.

Pulmonologist: Physician who specializes in diagnosis and treatment of disorders involving the lungs and respiratory system.

Quadripareisis: Partial paralysis or weakness of all four extremities.

Quadriplegia: Paralysis of all four extremities.

Range of Motion [ROM]: The amount a joint can be moved in one direction, usually measured in degrees.

Respiratory Therapist: A professional who provides treatments that improve or maintain breathing.
Rheumatologist:  Physician who specializes in the diagnosis and treatment of disorders involving the connective tissue, e.g., tendons and ligaments, and related structures of the body.

Scoliosis:  Curvature of the spine, usually a sideway curve, which may require the use of a body brace or surgery.

Sensory Defensiveness:  A negative reaction to sensory input ( e.g., textured materials, unexpected touch, high frequency noises) that is generally considered harmless or non-irritating by others.

Sensory Impairment:  Limitation in one or more of the senses, typically vision and/or hearing.

Spasticity:  Hypertonicity where there is excessive or tight muscle tone and resistance to passive movement.

Speech Therapist:  A speech language pathologist who provides evaluation and treatment of communication disorders.

Standard [Universal] Precautions:  Guidelines for infection prevention and control linked to specific policies and procedures that the staff are expected to apply in all care settings.

STD:  Sexually transmitted diseases (STDs) are infections that are passed from person to person through sexual or intimate contact between genitals, mouth, and/or rectum.  STDs include HIV/AIDS, gonorrhea, chlamydia, and syphilis.

Supine:  Lying on the back with the face up.

Surgeon:  Physician who provides operative treatments for injuries and disorders.

Technology Dependence:  A medical assistive device is required to replace or augment a vital body function, e.g., oxygen, ventilation, hyperalimentation.

Teratogen:  Agent in the environment of the developing embryo and fetus which causes structural or functional abnormalities, e.g., alcohol, illegal drugs such as cocaine, or prescription drugs such as Dilantin, Phenobarbital, anticancer drugs, etc.

Tetraparesis:  Partial paralysis or weakness of all four extremities; synonym for quadripareisis.

Tetraplegia:  Paralysis of all four extremities, See also: Quadruplegia.
**Universal Precautions:** See Standard [Universal] Precautions.

**Urologist:** Physician who specializes in the diagnosis and treatment of disorders involving the urinary tract in men and women and the male genital tract.

**Visually Impaired:** A limitation in the sense of sight.
Appendix B

Listing of Self-determination Curricula and Components

A curriculum guide for the development of self-determination and self-advocacy skills
AJ Pappanikou Center on Special Education
(860) 486-5035
Price: $15

A maze to amaze
Colorado Dept. of Education
(303) 340-7350
Price: $50

A road map for success: Setting goals and recruiting mentors
University of Illinois at Chicago
Price: $20

A student’s guide to the IEP
NICHCY (800) 695-0285
Price: $5

Become your own expert: Self-advocacy curriculum for individuals with learning disabilities
MN Dept. of Children, Families, and Learning
(651) 582-8515
Price: $23.95

Becoming self-determined
Educational Consultants of Madison
(608) 663-2303
Price: $89.95
Choosing employment goals
Sopris West Inc.
(800) 547-6747
Price: $95.00

Circles: Intimacy & relationships
James Stanfield
(800) 421-6534
Price: $599

Colorado transition manual
Colorado Dept. of Education
(303) 340-7350
Price: $30.00

Connections: A transition curriculum for grades 3 through 6
Colorado Dept. of Education
(303) 340-7350
Price: $30.00

Consumer leadership institute mentor training
VCU/RRTC
(804) 828-1851
Price: No charge

Fostering self-determination
Self-Determination Project
(907) 274-6814
Price: No charge

Group action planning: An innovative manual for building a self-determined future
Full Citizenship Inc
(785) 749-0603
Price: $25

I can do this! An Instructional unit in self-advocacy for students with disabilities
Spartanburg County School District
(864) 594-4400
Price: No charge
In their own words
Health Resource Center
(800) 544-3284
Price: $32

It’s my life: Preference-based planning for self-directed goal meetings
New Hats, Inc.
(435) 259-9400
Price: $25

It’s your choice: Planning for life after high school
Full Citizenship Inc
(785) 749-0603
Price: $60

Learning with purpose: An instructor’s manual for teaching self-determination skills to students who are at risk for failure
University of New Mexico
(505) 277-0119

Lessons for living: The 20 self-determination skills and self-advocacy for people with developmental disabilities: A trainer’s manual
James Stanfield Publishing Co
(805) 897-1185
Price: $149

Life centered career education: A competency based approach (5th Ed.)
Council for Exceptional Children
(888) 232-7323
Price: $980

Life centered career education: Modified curriculum for individuals with moderate disabilities
Council for Exceptional Children
(888) 232-7323
Price: $30

Making choices as we age: A peer training program
RRTCClearinghouse on Aging and DD
(800) 996-8845
Price: $55
Listings, Self-determination Curricula and Components

Metropolitan Nashville peer buddy manual
Metropolitan Nashville Peer Buddy Program
(615) 322-8186
Price: No charge

Moving on: Planning for transition from school to adult life
Colorado Dept of Education
(303) 340-7350
Price: $20

My choice; your decision
Advocacy Change Together
(800) 641-0059
Price: 4149.95

My voice, my choice: A manual for self-advocates
Human Services Research Institute
(617) 876-0426
Price: $179

Next S.T.E.P.: Student transition and educational planning
Pro-Ed
(800) 897-3202
Price: $144

Opportunities for daily choice making
American Association on Mental Retardation
(202) 387-1968
Price: $21.95

Parent education workbook for mainstreamed students, part 1: relationships; Unit 1: Understanding yourself
Iowa State University Press (available through ERIC)

PATH: Planning alternative tomorrows with hope. A workbook for planning possible positive futures
Inclusion Press International Voice
(416) 658-5363
Price: $15+5 S/H
Pathways to satisfaction
Educational Consultants of Madison
(608) 663-2303
Price: $149.90

Person-centered planning for later life: A curriculum for adults with mental retardation
RRTCClearinghouse on Aging and DD
(800) 996-8845
Price: $55

Problem solving for life: Teaching problem solving to adults with developmental disabilities
Clinical Center for the Study of Development and
(919) 966-4846
Price: $20

Project partnership: A model program for encouraging self-determination through access to the arts
Very Special Arts Educational Services
(202) 628-8080

Putting feet on my dreams: A program in self-determination for adolescents and young adults
Portland State University
(503) 725-4486
Price: $30

Rocketing into the future: A student conference launching kit
MN Dept. of Children, Families, and Learning
(800) 652-9024
Price: $8.95

Self-advocacy strategy for education and transition planning
Edge Enterprises, Inc.
(785) 749-1473
Price: $15

Self-advocacy: Leadership institute
VCU/RRTC
(804) 828-1851
Price: No charge
Self-determination for youths with disabilities: A family education curriculum
University of Minnesota
(612) 624-4512
Price: $10

Self-determination profile, it’s my life preference: Preference based planning, my life planner, profile decks, and dignity based models
New Hats, Inc.
(435) 259-9400
Price: $360

Self-determination training: Journey to independence
Iowa Department of Education
(615) 281-4114

Self-determination: A resource manual for teaching and learning self-advocacy skills
People First of Washington
(509) 758-1123
Price: $6

Self-determination: The road to personal freedom
Protection and Advocacy System
(505) 256-3100
Price: $35

Self-directed IEP
Sopris West Inc.
(800) 547-6747
Price: $120

Self power: A self-advocacy book for children with special needs
People First of Washington

Speak up for yourself and your future! A curriculum for building self-advocacy and self-determination skills
Enabling Futures Project
(802) 241-2417
Price: $22
Steps to self-determination: A curriculum to help adolescents learn to achieve their goals
Pro-Ed
(800) 897-3202
Price: $94

Student strategies: A coaching guide
Irvine Unified School District
(949) 936-5264
Price: $75

Take action: Making goals happen
Sopris West Inc.
(800) 547-6747
Price: $95

TAKE CHARGE
OHSU Center on Self-Determination
(503) 232-9154
Price: $ 65

TAKE CHARGE for the future
OHSU Center on Self-Determination
(503) 232-9154
Price: $45

Teaching choices: A curriculum for persons with developmental dis-abilities
Little Friends Inc.
(630) 355-6533
Price: No charge

Teaching problem solving to students with mental retardation
American Association on Mental Retardation
(202) 387-1968
Price: $21.95

Transition issues: A curriculum guide for independent living
Colorado Dept. of Education
(303) 340-77350
Transition to independence (3 Volumes: Becoming the me I want to be; Making choices; Building skills)
Spina Bifida Assoc.
(502) 637-736
Price: $20

Transition to post-secondary learning
Eaton Coull Learning Group, LTD
(604) 7334-5588
Price: $139.95

We can do it: A curriculum for teaching self-determination
Minnesota Educational Services
(800) 652-9024
Price: $6.50

Whose future is it anyway? A student directed transition process
The Arc National Headquarters
(817) 261-6003
Price: $20

Winchester follow-up self-advocacy institute
VCU/RRTC
(804) 828-1851
Price: No charge

Adapted from Wood, Test, Browder, Algozzine, & Karvonen, UNC Charlotte Self-Determination Synthesis Project (1999).
Appendix C

Helpful Health and Medical Resources

AHEAD- Association on Higher Education and Disability
http://www.ahead.org/

Centers for Disease Control and Prevention
http://www.cdc.gov

Clinical Pharmacology Online
http://www.cponline.gsm.com/

Consumer Information Center
http://www.pueblo.gsa.gov/

Disabled Sports USA (DS/USA)
http://www.dsusa.org/-dsusa

The Family Village
http://www.familyvillage.wisc.edu/

Financial Aid for (Post-secondary) Students with Disabilities
http://ericec.org/faq/finance.htm
From ERIC Clearinghouse on Disabilities and Gifted Education

Health World Medline Access
http://www.healthy.net/library/search/medline.htm

HEATH Resource Center
http://www.acenet.edu
The Institute for Child Health Policy
http://www.ichp.edu/

The Internet Drug Index
http://www.rxlist.com/

Internet Resource for Special Children (IRSC)
http://www.irsc.org/

Medicine Net
http://www.medicinenet.com/

Mental Health Net
http://www.cmhc.com

Neuroscience Now
http://www.neuroguide.com/

On-line Medical Dictionary
http://www.graylab.ac.uk/omd/index.html

On-Line Medical Journal
http://www.gretmar.com/webdoctor/index.html

PubMed – From the National Library of Medicine

The President’s Council on Physical Fitness and Sports
Box SG, Suite 250, 701 Pennsylvania Ave., SW, Washington, DC 2004

RxMed
http://www.rxmed.com/prescribe.html

Social Security Administration
http://www.ssa.gov

http://funrsc.fairfield.edu
Educational site about growing up with medical problems; includes bios of teens with various conditions.
http://www.ablelink.org
A bulletin board that puts kids with disabilities in touch with other kids; comprehensive set of links to other health and disability sites.

http://depts.washington.edu/healthtr
Practical tools: skill checklist and tips for teens, transition timeline, information for professionals and families.

http://www.nscd.org
National Sports Center for the Disabled provides updated information (including teaching skills, techniques, and adaptive equipment) on innovative outdoor recreation for children and adults with disabilities.

http://www.indiana.edu
Provides technical assistance to organizations that are designing and retrofitting leisure area and programs for accessibility.

http://www.nichcy.org/pubs/transum/ts8txt.htm
NICHY site. Presents information on the regulations and requirements for transition services and examines suggested transition components such as employment, post-secondary educational activities, independent living, eligibility for various adult services, and community participation.

http://www.nichcy.org/pubs/transum/ts7txt.htm
NICHY site. Development to help youth with disabilities, their families, and the professionals who work with them plan for transition. An overview of adult services systems(e.g., Social Security Administration, Vocational Rehabilitation) is given. Employment options are also explored.

NICHY site. Step-by-step guidelines are given to lead students through the process of learning about how the IEP is developed, learning about their disability, listing their strengths and weaknesses, identifying accommodations they need, developing a list of goals and objectives for the year, talking with teachers and parents, and preparing for and participating in the IEP meeting.
Appendix D

Health and Medical Provider Feedback Postcards
Thanks for working with me. It makes the ride so much smoother.

You saw the best in me, even though I was at my worst. Thank you, so very much!

We rest much easier, because you were there when we needed you.

Because you can see my possibilities - I just may be able to fly higher.

Thank you.
Bad Day Award

As a professional working with parents like me, you have a long way to go in order to make a positive difference in our lives.

- Just thought you'd like to know.

Perox

No compliments today. You were insensitive to my concerns as a parent. I encourage you to grow.

You deserve the Outstanding Professional Award for the way you work with parents like me. I appreciate you and I thank you.

SHAME ON YOU!

You treat me like a non-person.