



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



*A Guide for
Teenagers and Their
Families*

Human Development Center
Louisiana's University Affiliated Program
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

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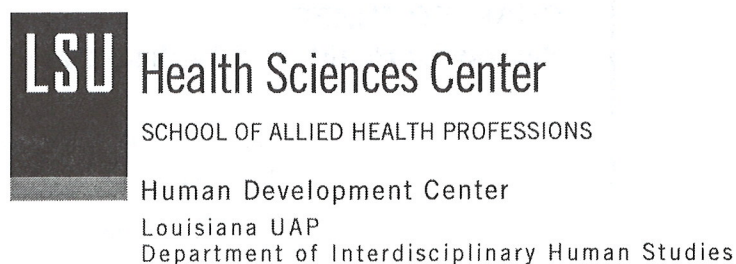
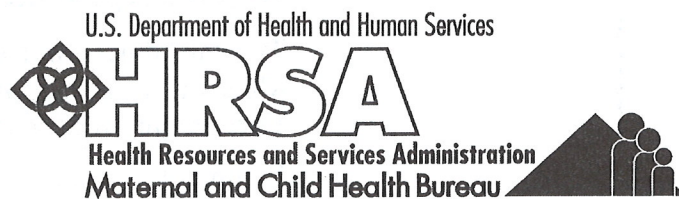
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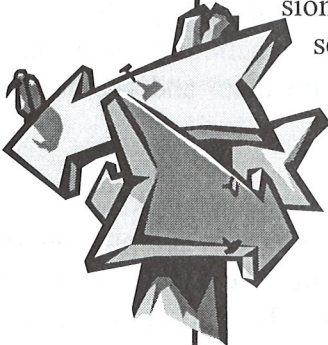
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CHAPTER ONE

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 decision-making in sensitive areas, such as sexual and reproductive health, nutrition, fitness, financial and estate planning, employment, postsecondary education and independent living. Teenagers must make many decisions as they prepare to leave high school and transition to employment, postsecondary 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 health care needs, finding the answers to these questions may raise even more questions and result in fear, anger, frustration and confusion.

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

"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 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 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, postsecondary 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.

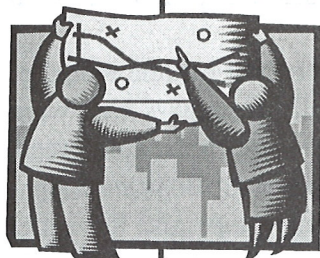
Thinking and talking about health and medical issues are essential parts of comprehensive transition planning, but they are often overlooked or given only a few minutes of attention during IEP meetings. This may be because health and medical questions are considered very personal, something to be discussed 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.

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

Many teenagers with disabilities and/or 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, 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 health care needs, are expected to transition from the pediatric health care system to the adult health care system around age 21. 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.

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 will also take place across multiple school years, resulting in implementation of a comprehensive and longitudinal plan.



Creating a Health and Medical Map

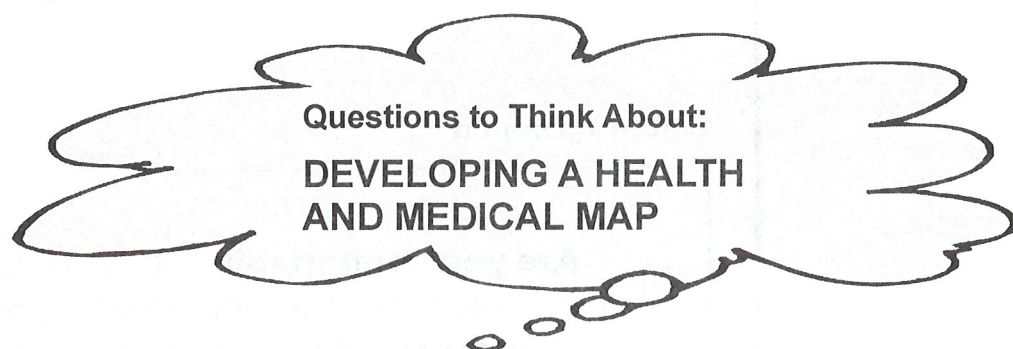
Thinking about, talking about, and planning for transition are important for all teenagers as they prepare to leave high school. In Louisiana, as in most states, teenagers reach the **age of majority** at age 18. This means that they have a legal right to make all decisions, including health and medical 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 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. 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 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, on pages 5 and 6, 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 forum. Appropriate forums might include, for example, meetings with other family members, IEP meetings, as part of a high school course, with support groups and/or with the health and medical professionals primary to their care.

Figure 1.2, on page 7, 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.

Figure 1.1



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?
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?

Figure 1.1 cont'd

- 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?**

Figure 1.2

DARNELL'S HEALTH AND MEDICAL MAP

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, and handling my insulin needs.

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, postsecondary 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.

CHAPTER TWO

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 a disability and/or 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 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 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, on page 11, 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 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 2.1 Strategies for Encouraging Health and Medical Independence Among Adolescents

TYPICAL ADOLESCENT EXPERIENCES	RELATED HEALTH AND MEDICAL NEEDS/STRATEGIES FOR ENCOURAGING INDEPENDENCE
<p>Physical Changes</p> <p>Growth Spurts</p> <p>Increased Body Hair</p> <p>Changes in Body Size and Shape</p> <p>Changes in Sexual/Reproductive Organs</p> <p>New Hygiene/Self-Care Needs</p>	<p>Are there any developmental considerations associated with specific disabilities, syndromes or medical conditions?</p> <p>Do changes in height/weight require changes in medication or treatment?</p> <p>Is there a need to discuss sexual/reproductive health questions/concerns?</p> <p>Is there a need for skill training for new hygiene skills, for example, shaving, use of deodorant, menstrual care, etc.?</p> <p>Is there a need to discuss the roles of Personal Care Attendants (PCA's)/other professionals in assisting with hygiene/self-care needs?</p>
<p>Emotional Changes</p> <p>Increased Sexual Feelings and Interests</p> <p>Need to Understand/Handle New Emotions</p>	<p>Is there a need to discuss sexual/reproductive health questions/concerns?</p> <p>Is there a need to discuss appropriate/inappropriate touching/sexual abuse?</p> <p>Is there a need to discuss feelings of depression/suicide?</p> <p>Is there a need to discuss/role play dating behaviors/etiquette?</p>
<p>Social Changes</p> <p>Learning to Interact with Peers</p> <p>Learning to Interact with Parents/Other Adults</p> <p>Establishing Personal Values/Beliefs</p>	<p>Is there a need to discuss/role play dating behaviors/etiquette?</p> <p>Is there a need for alcohol/substance abuse education?</p> <p>Is there a need to discuss/role play workplace behaviors/etiquette?</p> <p>Is there a need to discuss family, peer and personal values/beliefs?</p> <p>Are their cultural/ethnic values/beliefs that need to be taken into consideration?</p>
<p>Intellectual Changes</p> <p>Ability to Think More Abstractly</p> <p>Ability to Engage in More Problem-Solving/Decision-Making</p> <p>Ability to Self-Manage Resources</p>	<p>Is there a need to discuss/support the growth of self-determination skills/behaviors?</p> <p>Is there a need to address educational curricula, courses and postschool goals?</p> <p>Is there a need to address necessary supports to ensure postsecondary educational success?</p> <p>Is there a need to provide additional training/experiences in, for example, money management and medication management, etc.?</p> <p>Is there a need to provide appropriate and mutually-agreed upon opportunities for risk-taking?</p> <p>Is there a need to provide opportunities to interact with adult mentors with similar disabilities and/or health care needs?</p>
<p>Nutritional Changes</p> <p>Interest in/Need for Athletics/Exercise Routines</p> <p>Learning to Make Nutritional Choices</p>	<p>Is there a need to discuss athletics/exercise interests/adaptation needs?</p> <p>Are there any nutritional considerations associated with specific disabilities, syndromes or medical conditions?</p> <p>Is there a need to discuss nutritional needs/independent grocery shopping/meal preparation?</p> <p>Is there a need to discuss eating/weight management behaviors?</p>

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, on pages 13-15, 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.

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 2.2 Checklist of Typical Adolescent Health and Medical Skills and Behaviors¹

SKILL OR BEHAVIOR	I do this independently.	I can do parts of this independently or some of the time, but I need practice or support.	I cannot do this at all or can only do this with support.	This is a skill or behavior that I would like to address in my IEP transition services and/or with my health care professionals
I can describe my disability and/or health and medical condition.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I can describe the implications of my disability and/or health and medical condition on my daily life and activities.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I access/understand my health and medical records.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I take responsibility for taking my own medications.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know how to use/read a thermometer.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I take responsibility for doing my own medical treatments.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I take responsibility for scheduling my own medical/dental appointments/treatments.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I take responsibility for getting to/from my appointments.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I take responsibility for getting my own prescriptions filled.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know my height, weight, birthdate, blood type, allergies, etc. and/or I carry the information in my wallet.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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 Behaviors¹

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

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 Behaviors¹

SKILL OR BEHAVIOR	I do this independently.	I can do parts of this independently or some of the time, but I need practice or support.	I cannot do this at all or can only do this with support.	This is a skill or behavior that I would like to address in my IEP transition services and/or with my health care professionals
I can do simple repairs on my wheelchair or other assistive equipment and/or I know where/whom to call.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I understand the employment-related mandates of the Americans with Disabilities Act (ADA) as they concern my disability and/or health/medical condition.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I understand/am comfortable talking to potential employers and/or postsecondary education programs about my disability and/or health/medical condition/support needs.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
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Other:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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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 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 turn 18. Families with private insurance 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 children with and without disabilities, who are 18 years and older may remain on the family's policy until age 25 if they enroll full-time in a postsecondary education option. 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 health care needs. Medicaid is also the primary health care option for many unemployed or underemployed adults with disabilities and/or 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 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 or 888/342-6207) or <http://www.dhh.state.la.us>. 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 policymakers.

Summary

Obtaining and maintaining insurance to cover health and medical care is a major transition planning concern for teenagers with disabilities and/or 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.

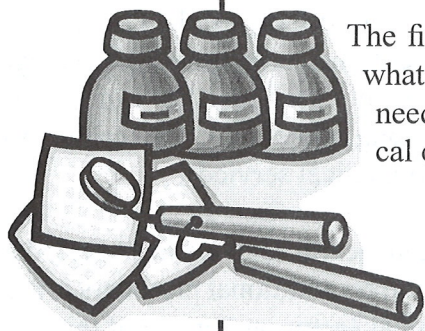
Availability of insurance is the foundation for the next step in the process. This step, choosing and working with health and medical care providers, is discussed in Chapter Four.

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 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 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 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, at 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 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 dietitian, 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 on page 21. Information on additional providers is included in Appendix A, Glossary of Health and Medical Terms, at the end of this manual.

Table 4.1
Overview of Health and Medical Providers¹

HEALTH /MEDICAL PROVIDERS	ROLE	TYPICAL SERVICES
Family Practitioner	<i>Physician or Nurse</i>	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.
Dentist	<i>Dentist</i>	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.
Dietician	<i>Nutrition Counseling</i>	Provides assistance with nutritional needs, menu planning and eating disorders.
Gynecologist	<i>Physician</i>	Provides regular care for females (i.e., breast exams, pap smears, birth control measures, pregnancy and prenatal care.
Neurologist	<i>Physician</i>	Monitors status of nervous system (i.e., nerves, spinal cord and brain) and treats problems.
Neurosurgeon	<i>Physician</i>	Specializes in the operative treatment [surgery] of disorders involving the nervous system (i.e., nerves, spinal cord and brain).
Occupational Therapist	<i>Therapist</i>	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).
Ophthalmologist	<i>Physician</i>	Monitors visual status and treats problems with structure, functions and diseases of the eye. May prescribe and check eyeglasses, treatments, and/or perform surgery.
Orthopedist	<i>Physician</i>	Monitors mobility status and treats skeletal problems (e.g., prescribes braces, adaptive equipment, therapy, etc.).
Physical Therapist	<i>Therapist</i>	Provides evaluation and treatment of gross motor functions. Home, school or center-based visits will be scheduled on regular basis (e.g., 2-3 times a week initially and reduced to quarterly for monitoring and follow-up).
Pulmonologist	<i>Physician</i>	Monitors status of lung and respiratory system and treats problems with breathing.
Urologist	<i>Physician</i>	Monitors status of urinary or urogenital systems (i.e., excretion and reproduction) and treats problems.

¹ Please refer to the glossary at the end of this manual for information on additional providers

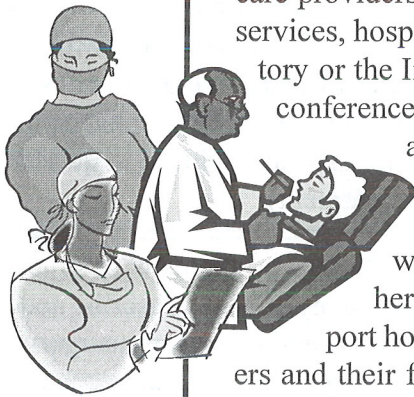
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Selecting Health and Medical Care Providers

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, on pages 23-25, 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.

QUESTIONS	COMMENTS
<p>1. Is the provider accredited, certified or licensed?</p> <p>What hospital(s) is the provider affiliated with? If they are accredited, certified or licensed, you have some assurance that they meet certain standards. If your insurance is to pay for this service, typically only accredited, certified or licensed providers are reimbursable.</p>	
<p>2. Are personnel trained/experienced in care of individuals with chronic illnesses or disabilities similar to yours?</p> <p>Consider not just the health and medical provider, but also the office and support personnel who may assist or be present when services are being provided.</p>	
<p>3. How will untrained personnel be educated?</p> <p>Are you expected to train individuals about specific disability characteristics and needs or will problems be addressed as they are identified through communications with experienced personnel, patients or families, professional in-service training, library research, etc.?</p>	
<p>4. What services are provided?</p> <p>Does this provider offer office visits, emergency care, and/or hospital care? Can all your equipment and supply needs be met by this one provider? Does a home health agency provide RN, LPN, home health aide, OT, PT, speech, equipment and/or supplies? Most young adults and families prefer to deal with as few providers as possible, whereas others choose to use more than one provider in order to get the least expensive services and equipment. The latter option often takes more management time and effort.</p>	
<p>5. Is there flexibility in scheduling?</p> <p>Is the provider's schedule convenient to your schedule? Are other options available?</p>	

Table 4.2 Checklist for Choosing and Working with Health and Medical Care Providers

QUESTIONS	COMMENTS
<p>6. What provisions can be made for coordination of care?</p> <p>How will your existing records be obtained? How will your current records be shared with other providers? You may be able to make arrangements to have certain information shared on a regular basis or you may choose to authorize these arrangements on an “as needed” basis.</p>	
<p>7. How dependable is coverage for regular and emergency situations?</p> <p>How is coverage handled at night, on weekends or during the provider’s vacations? What would you have to do? If you use life support equipment, e.g., oxygen or ventilators, what does the vendor do in the event of an equipment failure? Does the company provide a loaner while equipment is being repaired? What hospital(s) do they serve?</p>	
<p>8. Is the provider located in a convenient, accessible place?</p> <p>Are the building and office accessible? Do you have transportation to get the services or will they come to you?</p>	
<p>9. How is the plan of care for each individual developed?</p> <p>Who develops it? How much input can you have into your plan of care? Look for consideration of your knowledge and experience, want and needs, family situation and resources? If disagreements emerge, how are they resolved?</p>	
<p>10. What is the cost for the services and how will it be paid?</p> <p>Are you expected to pay for services as they are provided or will your insurance provider be billed? Your insurance company may limit your choices; however, you should be knowledgeable and comfortable with the process the provider uses.</p>	

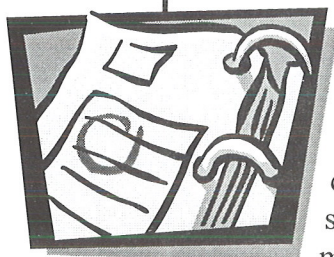
Table 4.2 Checklist for Choosing and Working with Health and Medical Care Providers

QUESTIONS	COMMENTS
<p>11. Will they share references with you from other professionals, agencies, patients and/or other families?</p> <p>The recommendations or comments of other individuals can give you information about how the provider works with other professionals, young adults with similar wants and needs and other families.</p>	
<p>12. What hospital is the provider affiliated with?</p> <p>Are all required hospital facilities accessible? Are the hospital's policies family- and disability-friendly?</p>	

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, on pages 27-29, provides a personal skills checklist for teenagers and their families to consider as teenagers begin to assume responsibility for managing all or parts of their health and medical needs and care.

Table 4.3 Personal Skills Checklist: Managing Health and Medical Care Needs

Skill or Behavior	I do this independently.	I can do parts of this independently or some of the time, but I need practice or support.	I cannot do this at all or can only do this with support.	Is this a priority?
ORGANIZE RECORDS				
I organize and maintain important records, such as my medical history, immunizations, doctors' visits, health treatments, medications and allergies.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
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.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
DECIDE WHEN AND WHY APPOINTMENTS ARE NECESSARY				
I know how often I should schedule routine check-ups with my primary physician.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know how often I should schedule check-ups with specialists.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I recognize and can describe my own disability and/or health condition.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I recognize early signs and symptoms of disability or health problems.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I respond appropriately to these signs and symptoms by making appointments with appropriate provider(s).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

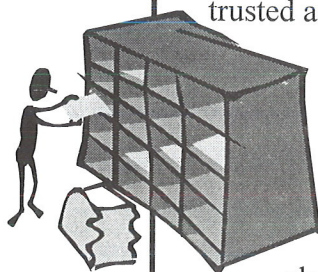
Table 4.3 Personal Skills Checklist: Managing Health and Medical Care Needs

Skill or Behavior	I do this independently.	I can do parts of this independently or some of the time, but I need practice or support.	I cannot do this at all or can only do this with support.	Is this a priority?
MAKE APPOINTMENTS				
I know whom to call, when to call and how to call to make any necessary appointments.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I can share all necessary medical information from my records.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I can describe my signs and symptoms to the receptionist or nurse.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I can make transportation arrangements.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I can describe any special accommodations or needs.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I can follow all pre-appointment requirements.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
PREPARE FOR APPOINTMENTS				
I can confirm transportation arrangements.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I can confirm the date, time, location and pre-appointment requirements.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I can collect all of my records and medications and carry them to the appointment.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I can make and bring a list of questions to ask the provider.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I can identify someone to accompany me to the appointment if that would make me feel more comfortable.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Skill or Behavior	I do this independently.	I can do parts of this independently or some of the time, but I need practice or support.	I cannot do this at all or can only do this with support.	Is this a priority?
COMMUNICATE WITH PROVIDERS AND FOLLOW PRESCRIBED TREATMENTS AND CARE				
I can communicate my questions and concerns to the provider.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I can ask questions about prescribed tests, medications, side effects and surgical procedures.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I can write down information about post-appointment needs.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I can follow any post-appointment procedures.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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, 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, 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 what ever 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

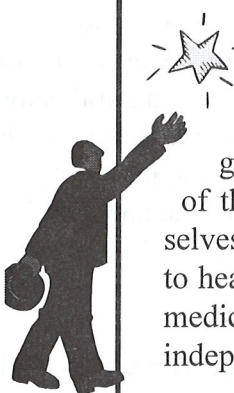
Choosing and working with health and medical providers are important tasks in making the transition from the pediatric to the adult health and medical care. For young adults and their families, this process can be traumatic and, thus, may not be addressed until several years later when young adults may 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 health care needs.

CHAPTER FIVE

Self-determination in Health and Medical Care

As we have seen throughout this manual, adolescence is a time of many changes for young adults with disabilities and/or health care needs. Helping adolescents to develop self-determination beliefs, knowledge and skills is an important component of overall transition planning; helping them use self-determination to more successfully transition from pediatric to adult health and medical care is an essential, but all too often overlooked, component of self-determination.

What is Self-determination?



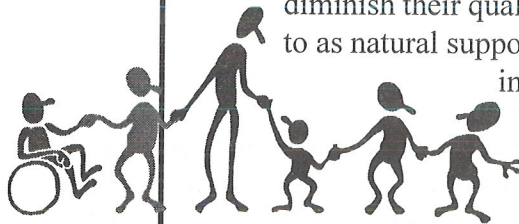
Self-determination may be defined as a combination of beliefs, knowledge and skills that enable a person to engage in goal-directed and independent behavior. Self-determined young adults review choices, make decisions, set goals, solve problems, evaluate themselves and attain goals. They are aware of 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.

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.

Assessing Self-determination in Health and Medical Care

Building self-determination in adolescents begins with assessing their abilities, Table 4.3 (pages 27-29). 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, baby-sitters, 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 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, on page 37, provides some suggested strategies for systematically building the self-determination of teenagers with disabilities and/or health care needs.

Table 5.1 Building Self-Determination in Health and Medical Care

SELF-DETERMINATION, BELIEFS, KNOWLEDGE AND SKILLS	SUGGESTED STRATEGIES
Review Choices	<ul style="list-style-type: none"> • 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 health care needs.
Make Decisions	<ul style="list-style-type: none"> • 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.
Set Goals	<ul style="list-style-type: none"> • 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	<ul style="list-style-type: none"> • 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	<ul style="list-style-type: none"> • 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 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 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.

CHAPTER SIX

Living a Healthy Lifestyle

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 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 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 addresses 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 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 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.

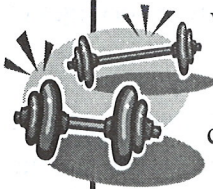
Exercise

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 health care needs, studies have found that they are even less likely to engage in regular exercise than their peers without disabilities or 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 health care needs should adopt an exercise regimen that includes stretching, deep breathing and isotonic activities to help promote flexibility, circulation and relaxation. For example, a 20-minute exercise program three times a week for a young adult might consist of weight training and aerobic exercise. Weight training or yoga, for example, will build up muscle tone and aerobic exercise will benefit one's heart, lungs and circulatory system. Depending upon the young adult's disability and/or health care needs and personal preferences, aerobic exercise might include, for example, cycling, swimming, cross country skiing, jogging, walking, dancing, or use of a stair climber.

Exercise programs do not require expensive tools, weights or other equipment. There are many commercially available and homemade options that can be used to enhance exercise. For example, books and videotapes can guide novices. Cans of food, books, bags of beans and frisbees, for example, can be used as weights. Many books, videotapes and supply catalogs describe exercise programs and assistive devices that have been designed for persons with limited mobility or upper or lower body movement.

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 in on an index card that can be visibly posted;
- (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) Remember that exercise should be fun.

Diet

Along with good hygiene and exercise, living a health 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, see figure 6.1 on page 43, to address healthy eating. This pyramid suggests a diet that includes five servings of fruits and vegetables daily and limited servings of fats, oils and sweets.

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:

- (1) Include low-fat and fat-free foods in your diet such as yogurt, cheese and other dairy products;
- (2) Include high-fiber and whole-grain foods such as cereals, fruits and vegetables;
- (3) Reduce portion sizes to help balance the required number of recommended food groups;
- (4) Make gradual changes in your eating habits until the new behavior becomes a habit; and
- (5) Allow your body to adjust to new foods.

Food Guide Pyramid

A Guide to Daily Food Choices

Fats, Oils, & Sweets
USE SPARINGLY

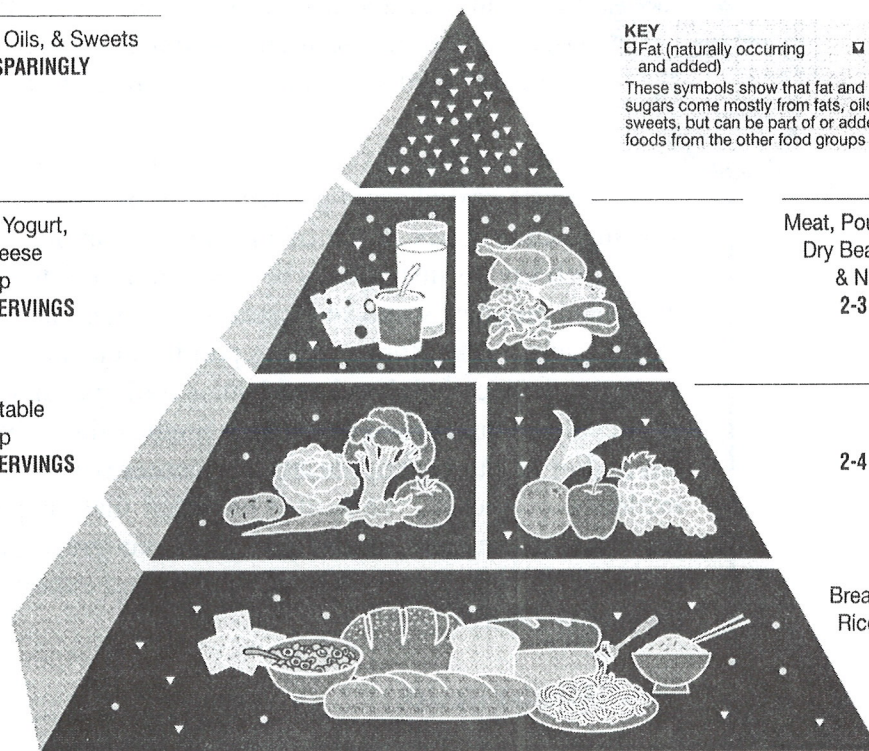
KEY
☐ Fat (naturally occurring and added) ☒ Sugars (added)
 These symbols show that fat and added sugars come mostly from fats, oils, and sweets, but can be part of or added to foods from the other food groups as well.

Milk, Yogurt, & Cheese Group
2-3 SERVINGS

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

Vegetable Group
3-5 SERVINGS

Fruit Group
2-4 SERVINGS



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

Bread, Cereal, Rice, & Pasta Group
6-11 SERVINGS

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.

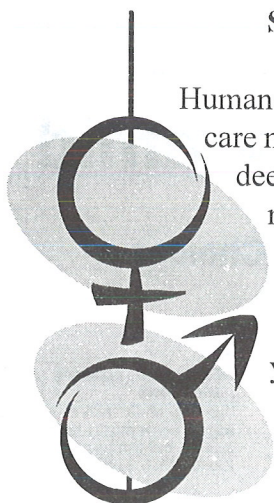
Each of these food groups provides some, but not all, of the nutrients you need. No one food group is more important than another — for good health you need them all. Go easy on fats, oils, and sweets, the foods in the small tip of the Pyramid.

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 1992, Leaflet No. 572

Figure 6.1

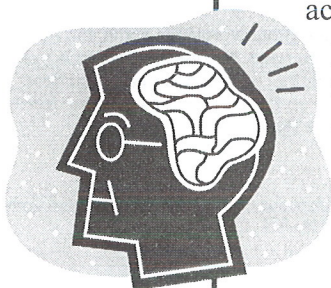
Sexuality



Humans are sexual beings, regardless of the presence of disabilities and/or 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 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. 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. Studies show that young adults with disabilities and/or health care needs are at a greater risk than their peers of being sexually exploited or abused. Thus, it is essential that, as part of the transition planning process, families and service providers recognize young adults as sexual beings and provide opportunities for discussion and experiences that are appropriate for the young adult.

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.

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. That is, 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.

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 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

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

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.

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 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, for example, 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**

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, for example, communication board, hearing aid, computer software, TDDs, etc.

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, for example, 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, for example, psychologist, psychiatric nurse practitioner, psychiatrist, social worker.

Deaf: Hearing impairment which is so severe that a person's hearing with amplified sound is not functional for the purpose of communication.

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 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 licensed physician and dispensed by a pharmacist. The physician may order the medication over the telephone or in writing.

Endocrinologist: Physician who specializes in the diagnosis and treatment of disorders involving the glands that produce hormones, for example, 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 activities of daily living, for example, 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 .

Gastronterologist: 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 individual in the family.

Gross Motor: Refers to coordination of the large muscles needed to perform activities of a daily living, for example, 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.

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.

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, for example, lungs, heart, intestines.

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, for example, the belly button or 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 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.

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 involved in primary eye care, including evaluating and prescribing treatments including corrective lenses and exercises.

Orientation and Mobility: Services provided to blind or visually 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: An abbreviation for the Occupational Safety & Health Administration, of the U.S. Department of Labor, which establishes regulations regarding health and safety in the work place.

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 eyes, 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. They focus on the person's neuro-skeletal-muscular function, and also assess the person's cardiopulmonary function and degree of general fitness. PT's 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, for example, 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 basis health care.

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

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 provided treatments that improve or maintain breathing.

Rheumatologist: Physician who specializes in the diagnosis and treatment of disorders involving the connective tissue, for example, tendons and ligaments, and related structures of the body.

Scoliosis: Curvature of the spine, usually a sideways 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.

Sensory Impairment: Limitations in one or more of the senses-vision, hearing, taste, olfactory, or tactile.

Sexually Transmitted Diseases [STD]: Illnesses passed from person to person through sexual or intimate contact with genitals, mouth, or rectum, for example, Congenital Infections, Cytomegalovirus, and HIV.

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

Speech Therapist: A speech language pathologist 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.

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, for example, 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- quadripareisis.

Tetraplegia: Paralysis of all four extremities, See also: **Quadriplegia**

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.

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

Price:

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

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 I: Relationships; Unit 1: Understanding Yourself

Iowa State University Press (available thru ERIC)

Price:

PATH: Planning alternative tomorrows with hope. A workbook for planning possible positive futures

Inclusion Press International Voice

(416) 658-5363

Price: \$15+5 S/

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

Price:

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

Price:

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 need

People First of Washington

Price:

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 disabilities

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
Price:

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 postsecondary 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, VNC Charlotte Self-Determination Synthesis Project (1999).

Appendix C

Helpful Health and Medical Resources

AHEAD- Association on Higher Education and Disability
<http://www.aheadorg/>

American Medical Association Medical Glossary
http://www.ama-assn.org/insight/gen_hlth/glossary/index.htm

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>

E-Medicine Searchable Text Book
<http://www.emedicine.com/cgi-shl/foxweb.exe/showsearch@d:lem/ga?book=emerg>

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

Financial Aid for (Postsecondary) Students with Disabilities

<http://ericec.org/faq/finance.htm>

From ERIC Clearinghouse on Disabilities and Gifted Education

Health Gate Medline Access

<http://www.healthcare.com/HealthGate/Medline/search.shtml>

Health Hotlines – Toll-Free Numbers from the National Library of Medicine

<http://www.sis.nlm.nih.gov/hotlines/>

Health World Medline Access

<http://www.healthy.net/library/search/medline.htm>

HEALTH Resource Center

HEALTH@ace.nche.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/>

Laboratory Tests

<http://kidshealth.org/parent/healthy/labtests.html>

Medicine Net

<http://www.medicinenet.com/>

Mental Health Net

<http://www.cmhc.com>

National Parent-to-Parent Support and Information System (NPPSIS)

<http://nppsis.org/>

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/journals.html>

PubMed – From the National Library of Medicine

<http://www.ncbi.nlm.nih.gov/pubMed/>

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>

<http://funrsc.fairfield.edu/~jfleitas/contents.html>

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://freenet.buffalo.edu-wnydf/>

The Western New York Disabilities Forum shares information related to physical, mental, and emotional disabilities.

<http://www.nscd.org/nscd>

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/-nca>

Accessibility (NCA) provides technical assistance to organizations that are designing and retrofitting leisure area and programs for accessibility.

<http://www.janweb.icdi.wvu.edu/kinder/>

Sponsored by National Institute on Disability and Rehabilitation Research, this site contains the American with Disabilities Act of 1990 (ADA) and ADA regulations and technical assistance manuals prepared by the US Equal Employment Opportunity Commission and the Department of Justice.

<http://www.disability.com>

Sponsored by Evan Kemp Associates, this site links people with disabilities and chronic health conditions to resources, products and services that promote active and healthy lifestyles.

<http://www.nichcy.org/pubs/transum/ts8txt.htm>

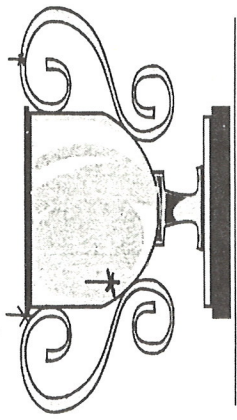
NICHY site. Presents information on the regulations and requirements for transition services and examines suggested transition components such as employment, postsecondary educational activities, independent living, eligibility for various adult services, and community participation.

<http://www.nichcy.org/pubs/transum/ts7txt.htm>

NICHY site. Development to help youth with disabilities, their families, and the professional 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.

<http://www.nichcy.org/pubs/stuguides/stbook.htm>

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, an preparing for and participating in the IEP meeting.



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.*

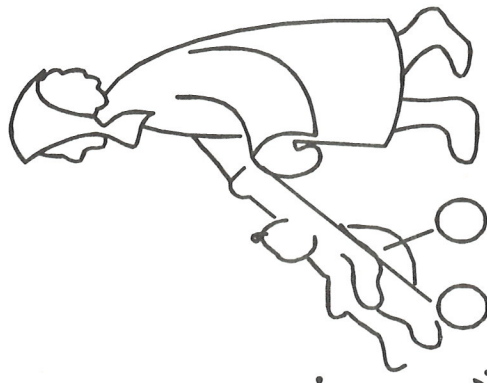
- Just thought you'd like to know.

Sorry

No compliments today.

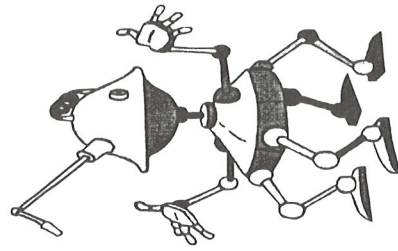
*You were insensitive to
my concerns as a parent.*

I encourage you to grow.



SHAME ON YOU!

**You treat me
like a
non-person.**



You deserve the

Outstanding Professional Award

*for the way you work
with parents like me.*



*I Appreciate you
and I Thank you.*

FROM:

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HERE

TO:

FROM:

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HERE

TO:

FROM:

PLACE
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HERE

TO:

FROM:

PLACE
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HERE

TO:

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

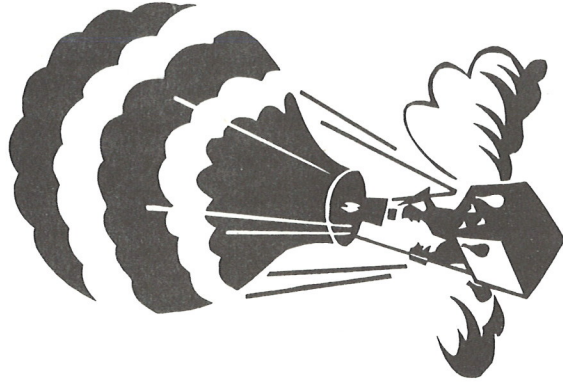


Thanks
for working
with me.

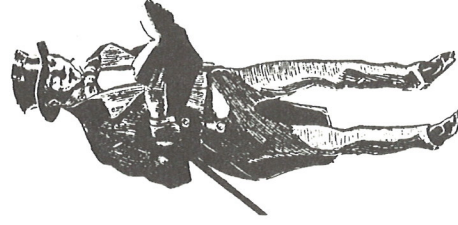


**IT MAKES THE RIDE
SO MUCH
SMOOTHER.**

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



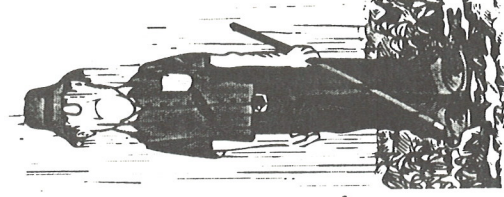
Thank ~ you



You saw the *Best*
in me,

even though

I was at
my Worst.



Thank - you, so very much!

FROM:

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