Journey to Adulthood

A Transition Travel Guide

Developed by:

Shriners Hospital for Children, Lexington

In Collaboration with
the
Kentucky Commission for Children with Special Health Care Needs
and the
Human Development Institute at the University of Kentucky

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Note for Health Care Professionals, Teachers, Family Groups and Others Working with Youth in Transition

This transition travel guide is designed to be used by **ANYONE, ANYWHERE, ANYTIME**. For many years the authors of this guide have been involved in developing and implementing transition programs and services at national, state, and local levels. What we have learned is that basic transition information does NOT change. Young people and their families must negotiate complex transitions in moving from pediatric to adult health care, school to work, and into the adult world healthy and ready to live as independently and inclusively as possible. There is no single route for all travelers. There are super highways and back roads. There are options to explore and points of interest along the way. What DO change on this journey are the services and resources. Just as gas stations come and go, transition programs and projects come and go as well.

Therefore the authors have developed a COMPREHENSIVE transition guide mapping out potential destinations, routes, points of interest and types of services and resources. Because this is a comprehensive travel guide, we encourage a quick overview of the topics included. A more in-depth study can occur as the transition plan unfolds. Not all teens and their families will need all the information in each chapter. However, we have tried to include information that will be helpful to most. We acknowledge that this transition guide is built on the work of many, and we are grateful for their contributions.

We have not included specific websites or contact information in the body of this travel guide with the hope that it will not become quickly outdated. Specific services and resources are found in a separate file of the on-line version and the back pocket of the printed version. We also encourage developing skills in using search engines to find out more about current services and resources.

We have also designed this travel guide to engage youth and their families in planning for the trip. Each chapter has transition activities designed to help youth and their families think through the many complex issues associated with transition. A trip worth taking is worth planning.

We invite ANYONE, ANYWHERE, ANYTIME to use this travel guide in whole or part, adapting it to meet the needs of youth and families served. We encourage those who use this travel guide to individualize the resource list as appropriate to their geographic location and populations served.

This travel guide can be found in both PDF and Word formats on the websites of Shriners Hospitals for Children, the Kentucky Commission for Children with Special Health Care Needs, and the Transition One Stop website of the University of Kentucky Human Development Institute.

December 2011

Introduction

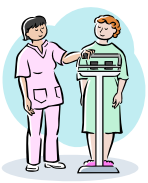
Life is full of changes….some are small while others are REALLY BIG. Bigger changes are often called TRANSITIONS. Examples of transitions are: starting or changing schools, graduating from high school, moving away from home, getting a job, moving from one place to another, changing doctors, getting married, or having children.

One of life's most complicated transitions is moving through the teen years into adulthood. Challenges include: figuring out how to make your own decisions and be your own person, learning to manage your health, and deciding how you want to live and what you want to do as an adult.

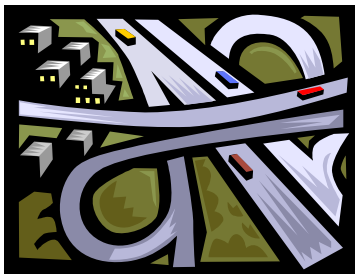
Transition to adulthood is a very exciting time! You will have more chances to be independent, try new things, meet new people, and become your own person! It can also be scary because of so many changes and new responsibilities.

There are many important questions to ask as you prepare for transition:

- What do I want to do after high school?
  - Do I want to go straight to work?
  - Do I want to go to college or another kind of work training?
  - Do I want to live at home or somewhere else?
  - What skills do I have that will help me do what I want to do?
- How will I stay healthy to have the life I want?
- How will I pay for everything I need and want?

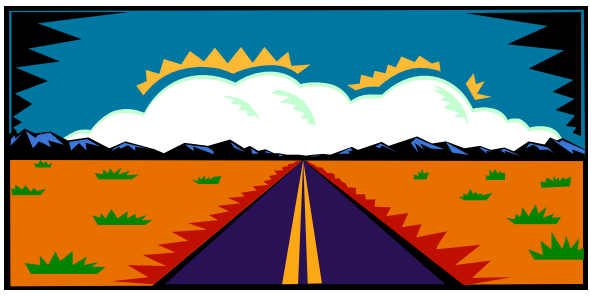


The purpose of this book is to provide you, your family, and others with a travel guide to plan this exciting “road trip” or “adventure” called transition to adulthood. It will help you ask and answer many questions about possible destinations and ways to get there. It will also help you learn about resources that are available along the way.



You can travel many roads to make the successful journey to adulthood. This book describes the major highways, on-ramps and fuel stops. It also alerts you to possible detours and roadblocks. We hope that it will help you prepare for your journey and reach your destination.

Life is always an adventure, and we wish you the best!



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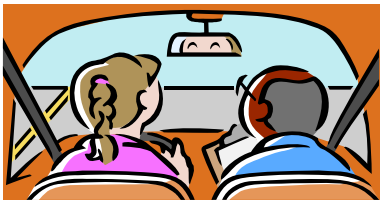
Resources for Roadblocks – in the Back Pocket or On-Line with this Book

Family Pages

Note to families and caregivers: This Transition Travel Guide is written for teens. However, you will want to be informed and involved as well. In some cases, your teen may need your help with reading and planning. In other cases, you may be doing most of the planning. The goal of this book is to identify landmarks on the journey to adulthood and provide a roadmap for transition planning. All good drivers need driver's education, and you are the driving coaches!



Tips for Preparing your Teen for the Trip

Start early and be positive about the future:

- Focus on your teen's strengths and skills
- Dream big….encourage being all he or she can be
- Talk with your teen about what he or she wants in the present and the future
- Encourage your teen to express his or her opinions
- Encourage reading, writing, and working with numbers
- Help your teen learn to problem solve
- Let your teen take some risks and deal with the consequences
- Build responsibility by having your teen do chores and volunteer work
- Encourage your teen to have friends
- Talk with your teen about friends and activities
- Encourage your teen to practice talking with people of all ages
- Remember that you are a role model for your teen
- Invite others into the planning process

Build independence at home. Teach your teen:

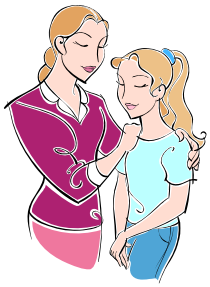
- Personal care and hygiene
- How to prepare meals
- Household cleaning and maintenance
- Care and washing of clothing
- Shopping and money management
- How to use basic tools and appliances

Work with health care providers:

- Encourage your teen to talk with health care professionals
- Let your teen spend time alone with his or her health care providers
- Encourage increasing self care, independence and responsibility for health matters
- Help your teen understand his or her health condition
- Help your teen keep health records
- Help your teen plan for emergencies and disasters
- Plan for a smooth transition to adult health care
- Explore health insurance options during the transition years

Work with the school:

- Encourage your teen to do his or her best in the classroom
- Encourage involvement in extra-curricular activities
- Talk about your teen's strengths, hopes and dreams with teachers and counselors
- Explore options for education, work, living arrangements, transportation, housing, recreation, and needed supports
- Be sure that planning for adulthood is started at school by age 14
- Encourage your teen to be involved in developing transition plans
- Learn about the resources that are available for transition
- Be your teen's advocate for services and resources



Help your teen become involved in the community:

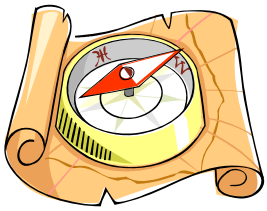
- Encourage hobbies and leisure activities
- Find volunteer or work opportunities
- Participate in community events
- Build a sense of community spirit, pride, and involvement
- Explore independent transportation options

Learn about transition resources in your state and community by reviewing this book and:

- Talk with teachers, counselors and health professionals
- Talk with other families and adults with disabilities who have been through the transition process
- Find resources using the internet

Read this book with your teen and talk about hopes and dreams for the future. Use it to ask questions and get information about health care, school, work, transportation, housing, money, and fun. Work through the transition activities together. Look at ***Resources for Roadblocks*** for help. Hopefully, you and your teen will have exciting adventures on the road to the future.

Chapter 1:
Deciding Where You Want to Go and Mapping the Route



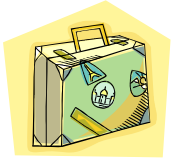
Planning for your future begins with YOU. You have both the right and responsibility to direct your life to the greatest extent possible. You will want great coaches, family and friends to provide guidance and input.

Remember, it is your life and your future! You are going to be the one living it!

> **A self-determined person is someone who sets his or her own goals, makes decisions, sees options, solves problems, and speaks up for him or herself. That person understands what supports are needed for success and knows how to evaluate options.**

The time to learn how to be self-determined is during your teen years as you are preparing for adulthood. It takes a long time to master all of these skills. So, start early, practice regularly, and get feedback from trusted others about how you are doing!

To begin planning for the future, it is important to understand who you are and what you want. Then you will be able to talk with others and speak up for yourself.



Transition Activities:

- Answer these questions to explore who you are and what is important to you.

Hopes and Dreams

What do I want my future to look like?

Strengths and Abilities

What am I good at?

What would I like to learn to do?

Planning for the Future

Does my disability or special need affect planning for my future? How?

At school, who is responsible for working with me to plan for transition? Who else can help me plan for my future?

Goals

Based on your hopes, dreams, skills and abilities, what are your goals for your future?

- Look at the transition plan on the next page. Write your goals there. As you read this book, add details about how you will reach your goals. You may want to make copies of the Transition Plan so you can expand or change it over time. Take the goals you have written on this plan to your school transition meeting to see how you can work them into your formal transition plan. Also discuss your goals with your health care team. Your future goals may affect your medical treatment plan.

- As you think about the life you want to have:

  - Ask your family and friends to help you look at possibilities

  - Ask your teachers and counselors to help you review your school work to see your areas of interest and your strengths. Look for guidance from your transition team—parents/guardians; school psychologist; general education teachers; administrators; and other service providers, such as speech and language, physical and occupational therapists; and others who have worked with you.

  - Ask your doctors, nurses, care coordinators, and therapists to help you get ready for changes that come with adulthood

  - Look at ***Resources for Roadblocks*** in the back pocket or on-line for ideas.

Remember, you don't have to decide right now on what to do in the future, but you do need to start planning. Kids often dream of being big stars when they grow up. As a teen it is up to you, with the help of others, to honestly figure out how to build on your strengths to live the life you want to live. Very few of us ever become super stars, but most of us have the chance to pursue many of our dreams.

Transition Plan

Name_____ Date_____

Goals	Current plans and activities to reach this goal	People helping and contact information

Topics to Review:

Staying Healthy
Managing my Health Condition
Health Insurance
High School Goals/Plans
Work Plans
Education after High School
Independent Living
– housing, transportation, supports
Community involvement and fun

Transition Plan (*make extra copies)*

Name_____ Date_____

Goals	Current plans and activities to reach this goal	People helping and contact information

Topics to Review:

Staying Healthy
Managing my Health Condition
Health Insurance
High School Goals/Plans
Work Plans
Education after High School
Independent Living
– housing, transportation, supports
Community involvement and fun

Chapter 2:
Staying Healthy for the Road Trip

How am I going to stay healthy so I can enjoy the life I want?

What health care will I need?

Who will provide my health care when I am an adult?

How will I pay for my health care?

One of the most important things you can do to stay on the road is to take good care of yourself! People who:

- ♥ eat right with lots of fruits and vegetables,
- ♥ control their weight,
- ♥ exercise,
- ♥ wear seat belts,
- ♥ don't smoke cigarettes,
- ♥ have friends,
- ♥ stay busy,
- ♥ and get help when they need it

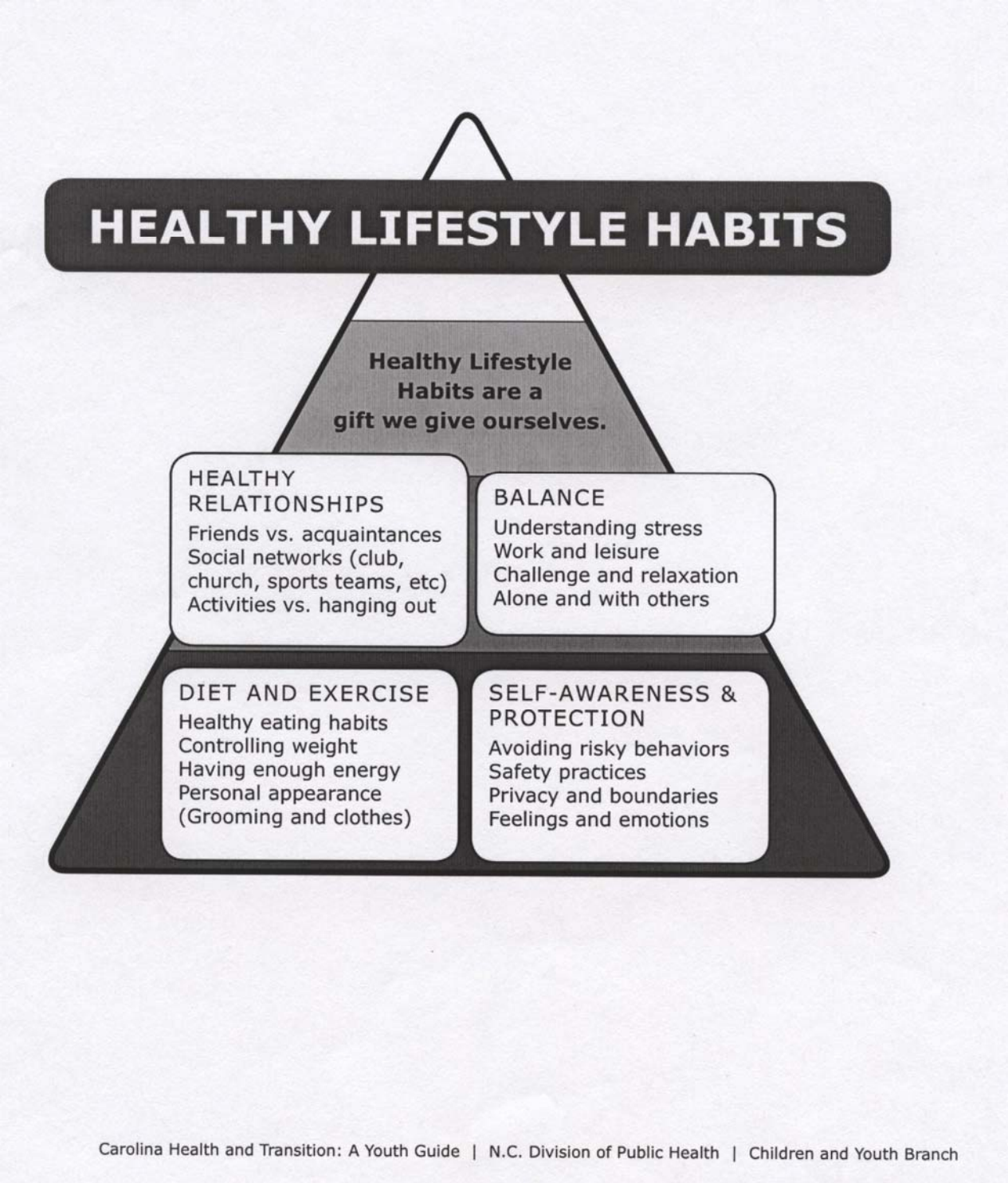
live longer and healthier lives than those who don't.

Some people with disabilities think that they can never be truly healthy. This thinking can lead to unhealthy choices because people with disabilities see their health as something they cannot control. Now we know that there is not a single definition of health for all people, but a healthy lifestyle is important for ***everyone!*** The following checklist will help you think about ways to stay healthy.

Complete this Checklist for Health and Wellness:

Health Factor	Concerns	Yes	No
Diet	Do I eat lots of fruits and vegetables each day? Do I limit fatty foods, snacks and sweets?	☐ ☐	☐ ☐
Body weight	Is my weight changing? Am I getting too heavy or too thin?	☐ ☐	☐ ☐
Water and fluids	Do I get 8 glasses of fluids per day? Do I drink enough water? Do I drink no more than 1 soda per day?	☐ ☐ ☐	☐ ☐ ☐
Teeth	Do I brush and floss daily? Do I see a dentist at least yearly?	☐ ☐	☐ ☐
Exercise	Do I get at least 30 minutes of exercise every day?	☐	☐
Sleep	Am I getting 7-8 hours of sleep each night?	☐	☐
Bladder and bowel function	Do I stay clean, dry and odor-free? Do I limit daily or social activities because of bowel or bladder issues?	☐ ☐	☐ ☐
Movement and function	Do I have strength to do what I want to do? Do I have pain? Is there a change in how I function (move, see, hear, muscle control and strength, etc)? Can I do today what I could do a year ago?	☐ ☐ ☐ ☐	☐ ☐ ☐ ☐
Skin	Are there any red places or broken areas on my skin?	☐	☐
Mobility and transportation	Do I get around in my home and school? Do I get around in my community? Can I drive or use public transportation?	☐ ☐ ☐	☐ ☐ ☐
Fun and friends	Do I have fun every day? Do I have friends I do things with?	☐ ☐	☐ ☐
Mental health	Am I happy? Do I like myself? Can I talk about what I do well? Do I have someone to talk with when I feel sad?	☐ ☐ ☐ ☐	☐ ☐ ☐ ☐
Sex	Do I need information about sex? Do I need information about how my condition might affect my sexuality or having children?	☐ ☐	☐ ☐
Tobacco, alcohol and drugs	Do I smoke or chew tobacco? Do I drink alcohol or take drugs? Do I know how these affect my overall health and health condition?	☐ ☐ ☐	☐ ☐ ☐
Screenings	Do I get regular health screenings - vision, hearing, blood pressure, breast or testicular exams?	☐	☐
Immunizations	Are my immunizations up to date? Do I have a list of them?	☐ ☐	☐ ☐
Wellness baseline function	Can I tell when something about my body is changing and I should see my doctor or nurse practitioner?	☐	☐
Culture	Do I know how my culture affects my health?	☐	☐

Look at this Healthy Lifestyle Habits Triangle. Think about your Healthy Lifestyle Habits!



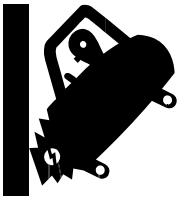
Transition Activities:

- Review the Checklist for Health and Wellness and the Healthy Lifestyle Triangle. Are there some areas where you need to change? Set some goals. Try to make the goals observable and measurable. (For example: I will drink 8 glasses of water on 5 out of 7 days next week, or I will make an appointment with a dentist today.) Make a list of at least 3 goals:

- Talk with your doctors, nurses or other health care professionals about ways you can get healthy and stay healthy.

- Some teens struggle with feelings of sadness, loneliness, and anxiety or feel depressed. Symptoms of depression can include: withdrawal from friends and family, changes in sleep and eating habits, problems at school, decreased energy, anger or irritability, or poor self-esteem. Talk with your parents, doctor, nurse practitioner, nurse, social worker, care coordinator, teacher or school counselor if you think you could be anxious or depressed. Help is available. **Don't try to deal with these feelings alone.**

As an adult, no one is going to make you take care of yourself. However, it will be hard to live the life you want to live if you don't stay healthy. Learn to work with your health care team so you can manage and improve your health.



Avoiding wrecks and long detours

Just as there are lifestyle choices you can make to stay healthy, there are lifestyle choices that can lead to serious wrecks, roadblocks or long detours. Smoking, drinking, drugs and irresponsible sexual activity all have serious consequences and can keep you from reaching your transition goals.

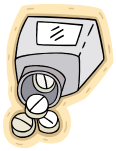
During your teen years there is a lot of pressure to "fit in". Unfortunately, one way to fit in is to get in with the wrong crowd doing the wrong things. Some teens with disabilities or chronic health conditions will be tempted. It is important to consider the costs and potential outcomes.

Do you know that smoking:

- ∇ Costs the average smoker (one pack a day) $2000 yearly? If this money was invested, at the end of 20 years you could have over $50,000.
- ∇ Is highly addictive, and many people can't give it up even when they want to?
- ∇ Takes 10 years off your life if you smoke a pack a day? Each cigarette shortens your life by 11 minutes!

Do you know that drinking alcohol:

- ∇ Can lead to alcoholism which is a highly addictive disease and destroys many people and their families?
- ∇ Clouds thinking and judgment and, in excess, damages the brain?
- ∇ Can damage your liver?
- ∇ Can interact with medications you may be taking and cause serious problems including death?
- ∇ While pregnant can cause your baby to have fetal alcohol syndrome which damages your baby's brain forever?



Do you know that drug use:

- ∇ Is illegal?
- ∇ Often leads to criminal activity to get the money to get more drugs?
- ∇ Tells your brain that getting the next high is the most important thing in your life?
- ∇ Robs people of their hopes, dreams, plans, and money?
- ∇ Can interact with medications you may be taking and cause serious problems including death?
- ∇ Can damage an unborn baby?

Do you know that irresponsible sexual activity can lead to:

- ∇ A baby which will cost the average middle income family $250,000 to raise to age 18? The first year alone can cost $11,000 or about $900 per month.
- ∇ Loss of your freedom because a baby requires care all day every day?
- ∇ Sexually transmitted infections including AIDS?

We hope that you will consider the costs carefully and make choices that will not end your trip suddenly and unexpectedly or take you on a long detour. Your future is at stake!

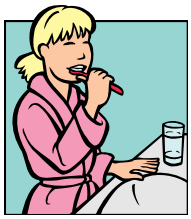
Transition Activities:

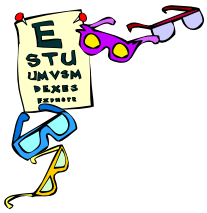
- Find out how smoking, drinking or doing drugs could affect your health condition?

- Can there be dangerous interactions between drugs and alcohol and the medications, food, or treatments you need?

- If you were to get pregnant, would any of the medications you take cause harm to your unborn baby?

- What questions do you have about sexuality in general OR about how your health condition affects sexual activity, pregnancy, or childbirth? Make a list of questions you would like to discuss with your doctor or nurse practitioner. If they don't know the specific answers, they will help you with a referral to someone who can answer your questions. **You have a right to know.**





Managing Your Health Condition and Special Needs

In addition to being smart about staying healthy, it is very important for teens to learn to manage their health conditions or disabilities so that they do not get worse or cause more problems.

When you were a child, your family took care of planning everything. As an adult, you will have this responsibility unless you give your parents permission to stay involved.

- What do you need to know and do to manage your health condition at home, in school, at work, and places out in the community with friends?
- Do you need to take medications, do therapies or treatments, or have a special diet?
- Where will you get health care?
- How you will pay for health care?

Health care professionals who care for adults have different expectations than those who care for children.

- They expect YOU and not your family, to do the talking unless someone in your family becomes your legal guardian.
- They expect YOU to take responsibility for following through on your plan of care.

- They expect YOU to do things to stay healthy, such as eating right, exercising, not smoking or chewing, not drinking, and not taking drugs.
- They don't call and check to see how you are doing. If you miss an appointment, YOU must reschedule.
- If there is something you want or need, they expect YOU to speak up.

Overall in adult health care, there is much less help in getting things done. Your teen years are the ideal time to prepare for what is expected when you start seeing health care professionals who care for adults. Before you enter the world of adult health care, learn about how to manage your health and health condition.

Who can help you do this? It may be the doctors, nurses, social workers, care coordinators, or therapists you see at children's hospitals or specialty clinics, and/or your **medical home**. A medical home is doctor, nurse practitioner, or clinic where you regularly go for checkups when you are well and for care when you are sick. Your medical home helps you get referrals to specialists and community services and coordinate your care.

It is important to start practicing early. Health care visits sometimes get rushed. Ask your health care providers to take the time to **talk transition!**

Transition Activity:

- Complete the Checklist for Managing a Health Condition or Disability on the next page by marking the box that you feel best describes where you are right now.

Checklist for Managing a Health Condition or Disability

Skill	Yes	No	Not needed for my care
I can explain my health condition or disability to others.			
I know how to get accurate information about my heath condition or disability.			
I can tell when there are changes in my health condition or disability.			
I know symptoms that need urgent medical attention.			
I have a plan for emergencies or disasters.			
I know the names and how to contact my doctors and other health care professionals.			
I carry a portable medical summary in my purse or billfold.			
I call to get my own health care appointments.			
I make a list of questions before visits to my health care professionals.			
I can fill out my medical history forms including a list of medications and allergies.			
I answer questions asked by the doctor, nurse or other health professionals.			
I see my doctor and other health care professionals alone for at least part of each visit.			
I co-sign the “permission for medical treatment” form or direct others to do it for me.			
I prepare and take my medications or direct others.			
I know what my medications and treatments are for.			
I know the side effects of my medications and possible interactions with food and other drugs.			
I call the pharmacy to refill my prescriptions before they run out.			
I do my treatments or direct others.			
I help monitor and maintain my medical equipment so it is in good working condition.			
I know how to contact the vendors who provide my equipment.			
I can order my medical supplies.			
I help to keep copies of my medical records and bills at home.			
I carry a copy of my insurance card.			
I know what my health insurance covers.			
I have a plan for health insurance after I turn 18.			
I have a plan for adult health care.			

Modified from JaxHats, HRTW, Sick Kids, PACER Center

Transition Activities:

- How did you do on this checklist? Pick out the skills that you would like to work on in the coming months. Write them here. Keep working on this list until you can do everything you need to do. Who can help you learn to do these things?

- How do you explain your health condition or disability to others?

- Sometimes family customs and beliefs affect health care decisions and medical treatments. Talk with your family about how your customs or culture or religion might influence the ways you think about your health, manage your condition, and the treatments you would accept.

- If you have a cell phone, enter in your ICE (In Case of Emergency) contacts. First responders such as paramedics, firefighters, and police officers look in cell phone address books under ICE for people who can provide important medical information when the person they are helping cannot. Make sure your ICE contacts know your "MAD" -- Medicines, Allergies and Doctors.

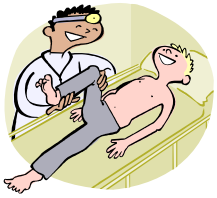
Remember you don't have to learn everything today, but you do need to set some goals. You will not be able to travel very far on your trip to independence if there is not gas in the car! Your health is the fuel that will get you to your destination.

Finding Adult Health Care Professionals

Without planning for transition, teens and families may be surprised when they are refused care at a doctor's office or a children's hospital because they have "aged out." You don't want to find this out when you are sick and need help really fast. Plan ahead! Start planning at age 16 for your transfer to doctors or nurse practitioners who care for adults. Actual transition is usually between ages 18 and 21.

Some young adults can have all of their adult health needs met by a family doctor or nurse practitioner, their **adult medical home**. Others will need referrals to specialists, such as orthopedists, urologists, cardiologists, or physical medicine and rehabilitation physicians. Your medical home will help you get referrals and coordinate care with these specialists.

You want your adult health care professionals to have experience in caring for adults with your disability or health condition AND take your health insurance. You also want someone who listens and takes time to answer questions and respond to your concerns.



Here are some tips for finding adult health care professionals:

- Ask your current doctors, nurse practitioners or care coordinators who they recommend.
- Ask adults who have health needs like yours who they see.
- Look at your health insurance company booklet or website for approved providers.
- Call and interview doctors or nurse practitioners. Find out if they have experience with your health condition, how long it takes to get an appointment, and how quickly you can be seen if you are sick.
- Use the internet. Look at websites of the American Academy of Family Physicians, American College of Physicians-Internal Medicine, American Academy of Physical Medicine and Rehabilitation, American Academy of Orthopedic Surgeons or other specialists needed for your care. Refer to ***Resources for Roadblocks*** for specific websites or "google" the type of specialist you need.

Transition Activities:

- Talk with your family and other health care professionals about the providers and services you will need when you become an adult (about age 18).

- Once you choose a new doctor or nurse practitioner, gather your past medical records for him or her. If you have lots of medical records, be selective and request discharge summaries from hospitalizations and the past 2-3 years of progress notes including labs and x-rays. Remember, you (or your legal guardian) will have to sign the release of information at age 18.

- One way to help your new *adult medical home* get "up to speed" about you is to prepare a medical summary. Copy the medical summary on the next pages (or the smaller one in the back pocket of this book) and complete as much as you can. Ask your doctors, nurse practitioners or care coordinators to help you complete the parts you are unsure about.

Medical Summary

Personal *Date* _____

Name _____ Birthdate_____ SS#_____

Address

_____

Street City State Zip

Phones _____ _____ E-Mail_____

Cell Home

Emergency Contact _____ Relationship _____ Phone_____

Guardian/Medical Surrogate_____ Relationship _____ Phone_____

Allergies (meds, food, environment and what happens)_____

_____

Communication/Language/Cultural Needs_____

Assistive Technology Used/Needed_____

Glasses ☐ Yes ☐ No Hearing/Aids ☐ Yes ☐ No ☐ Other _____

Special Dietary Needs_____

Height _____ Weight _____ Blood Type_____

Strengths/Assets_____

_____

Insurance:

Primary Insurance _____ _____ _____

Name ID# Group#

Case Manager _____ Phone #_____

Secondary Insurance_____ _____ _____

Name ID# Group#

Case Manager _____ Phone #_____

Information Sharing

Which family members, guardians, or other people are allowed to discuss your medical information with your doctor? If you are 18 or older, include them on your HIPAA privacy form.

Name_____Relationship_____Phone_____

Name_____Relationship_____Phone_____

Health Condition

Diagnosis or condition	Name of doctor or nurse practitioner	Contact information
Medical Home		
Dental care		

Hospitalizations (including surgeries) in Past Year – Start with most recent or last hospitalization if more than a year ago

Where	Reason	Date

Lab, X-ray Studies/Findings in Past Year

Test	For what reason	Results	Date	Where done

Current Medications

Name of medicine	For what reason	Amount (Dose) and how often	Doctor/Practitioner who prescribed

Name of Pharmacy_____ Phone_____

Current Therapies or Treatments

Type of therapy/treatment	Frequency	Provider	Contact information

Medical Equipment and Medical Supplies, Orthotics or Prosthetics

What	For what reason	Provider and contact information

Immunizations

Type	Date of last one	Type	Date of last one
Diphtheria, Pertussis, Tetanus (DPT/DTaP/Tdap)		Meningococcal	
Tetanus (Td)		Hepatitis B	
Polio		Hepatitis A	
Measles, Mumps, Rubella (MMR)		Human Papilloma Virus (HPV)	
Varicella (Chickenpox)		Influenza (Flu)	
Hib (Haemophilus influenzae type b)		Tuberculosis (Mantoux or PPD)	
Pneumococcal (PVC)		Other	

Activities of Daily Living

Activity	I can do	Need some help	Need lots of help
Grooming and personal hygiene			
Bathing			
Dressing and undressing			
Feeding self			
Transfers			
Bowel and bladder management			
Walking without assistive device			
Getting around with assistive device (crutches, walker, wheelchair)			
Get out in the community			

Future Plans

Topic	Plans	Referrals made & contact information
Health Care		
Health Insurance		
School & Work		
Housing		
Transportation		
Supports		
Other		

Additional comments (may use back of form):

_____

_____

_____

_____

Talking with your Doctors and Other Health Care Providers

Visits with doctors and nurse practitioners who care for adults are usually short. Learn to give information quickly, and be sure you understand what you are told.

When you go to the doctor or nurse practitioner, be prepared to talk about:

- "Chief complaint or concern" - why you came to see the doctor or nurse practitioner TODAY
- Current medications and treatments
- Past medical history - practice giving your medical history in 3 minutes
- Brief review of current information related to your health condition (what's new, how are you feeling, worries)
- Problems/concerns that you would like to talk about at a future visit if there is not time today
- Resources you need (equipment, supplies, services)

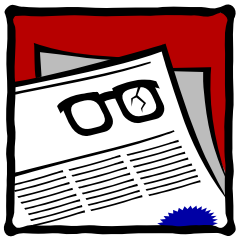
Ask questions about:

- The plan of care that your doctor or nurse practitioner recommends (medicines, labs, therapies, routines)
- Why this is the best plan of action
- What to do next, who will do it, and when

If you don't understand your doctor or nurse practitioner, you might say:

- Please tell me more about that.
- Could you write that down for me?
- Where can I find more information about this?
- Is there something you can give me to read?

Transition Activity: Role play a visit to your doctor or nurse practitioner using the information above as an outline.



Privacy of Health Information

In most states, before the teen's **18th birthday**, medical treatment requires parental consent except in very specific circumstances. The teen's verbal or written assent is recommended but not required.

On the young person's 18th birthday, legal responsibility for consent shifts to the young adult. Under HIPAA (the Health Insurance Portability and Accountability Act), health care professionals *cannot* discuss health information with their adult patient's parent or guardian ***unless the young person specifically grants permission*.** Strict adherence to HIPAA rules might mean that parents and guardians suddenly cannot get information about a teen's health and health care.

Managing this transition in decision-making and information sharing requires careful planning. Young adults may elect to sign a HIPAA waiver to give parents access to their medical information; however, there is no legal requirement that says they must.

Transition Activity: Ask your health care professionals for a copy of the HIPAA consent for treatment form that you will be asked to sign when you are 18. Discuss this with your parents or guardians, and together decide who should have access to your medical information.

Paying for Your Health Care

Having health insurance is important for young people with chronic health conditions or disabilities. Insurance affects the ability to get medical care, stay well and prevent further health problems. Health care funding changes often! For the latest laws affecting payment for health care for older teens and young adults, see ***Resources for Roadblocks,*** Chapter 2, under Health Insurance or "google" health insurance + young adults.

Health care insurance can be obtained through any of the following:

- Employer-based coverage through your parent's work or your own work

- A plan purchased directly from an insurance company but not through work (these are usually expensive).

- A government-sponsored health plan: Medicaid, Medicare, TRICARE (military), Children's Health Insurance Program (CHIP to age 19), or state children with special health care needs program (Title V CSHCN to age 21 in most states).

Medicaid is a government program which pays for medical services for individuals with disabilities with low incomes. Each state determines who is eligible, the scope of services, and payment for services. Some doctors do not take Medicaid.

Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) service is Medicaid's child health program for individuals under the **age of 21**. It includes periodic screening, vision, dental, and hearing services and any

medically necessary health care service. In some states EPSDT can cover in-home personal services or nursing care. It is important for teens and young adults to plan ahead for the transition from pediatric to adult Medicaid benefits because pediatric benefits are more generous. Consider the timing for getting diagnostic services and care, equipment such as a wheelchair, prosthetics or orthotics, glasses or hearing aids or other needed equipment.

Medicaid and SSI: **At age 18**, adult standards for disabilities are used. Many youth will no longer be eligible for SSI and may also lose Medicaid. Talk with someone at Social Security six months before your 18th birthday so you can plan ahead.

- Some youth with disabilities did not receive SSI or Medicaid because their parents made too much money. At age 18 they may qualify for Medicaid because their parents' income is no longer counted.
- People on SSI can work and keep Medicaid. Talk with a Benefits Counselor at the Social Security Administration or at a Center for Independent Living for more information.

Medicaid Buy-In: This is a program available in some states for working people with disabilities aged 16-65 who are not on SSI and earn income less than 250% of poverty level.

Special Medicaid Waivers

Each state has special Medicaid Waivers which provide Medicaid coverage for disabled persons who need intensive support to live at home. Without waiver services some persons would need care in a nursing home. If you have a disability and require lots of help with personal care or supports, ask about the waiver services in your state. Your doctors, nurses, social workers, or care coordinators should be able to point you in the right direction. Another way to get information is to "google" the term Medicaid Waiver + the name of your state. Waivers change so be sure the information is up-to-date.

Children's waivers are different from those for adults. Eligibility for some waivers change based on age. If you are currently receiving waiver services, find out if you "age-out" of your waiver program and what waiver programs are available for adults.

Services provided by waivers can include: personal care or attendant services, nursing care, therapy, home making, equipment and supplies, case management, minor home adaptations, and supports to help you be a part of your community. Not all waivers provide the same services, so it is important to explore all of the waivers in your state and see which would work best for you.

Some waivers have what are called "consumer-directed options" that enable you to hire someone to help you with your care. This person may even be a family member. Just as there are different waivers, there are different eligibility requirements. Some states have waiting lists to get on special Medicaid waivers. It is best to plan ahead and sign up early.

Children's Health Insurance Program (CHIP) is a state and federal partnership that targets uninsured children and pregnant women in families with incomes too high to qualify for most state Medicaid programs, but often too low to afford private coverage. In most states the CHIP program provides health care services to children and teens **up to age 19**.

State Children with Special Health Care Needs Programs

Each state combines federal and state funds to make sure there are comprehensive services for children with special health care needs. All states provide information and referral for diagnostic and treatment services and other resources. Some states provide direct services, such as specialty clinics, diagnostic screenings, care coordination and transition preparation. These state programs serve young people to **age 18 or 21**.

Medicare/ SSDI: Young people may qualify for Medicare through Social Security Disability Income (SSDI) because:

- they are "adult disabled children" of adult workers who have become disabled, retired, or deceased
- they have worked and paid into Social Security for two or more years and then become disabled. After receiving disability benefits for 24 months, they are eligible for Medicare.

Insurance Savvy: Things you should learn:

- Learn what services are covered under your insurance plan. Be clear about when coverage under that plan ends based on your age and school status. Read your insurance handbook to learn about your benefits and responsibilities; look for yearly open enrollment periods when you can sign up for or change coverage. Health care reform in 2010 requires family insurance plans to include children up to age 26.

- Adult Dependent Disabled Child. Some health insurance plans include a permanent dependent status for adult children who are dependent on family for care and finances. Often this means that the young adult is on SSI or meets the SSI disability definition, is not working full time, and lives at home. Sometimes there is only one time or one age you can apply. If you miss that time or age, your family can never apply again. Find out if this status applies to you and plan ahead.

- Use providers covered by your insurance plan and know if your medical home (primary care provider) needs to refer you to specialists. If you don't use providers in your network, you might get a big bill!

- Ask your doctor/nurse practitioner to prescribe medications on the discount lists at major pharmacies whenever possible. If paying for your medication is a hardship, ask your doctor for a referral to special programs through drug companies or other organizations that help those who cannot afford their medications. These programs may be called Prescription Assistance Programs.

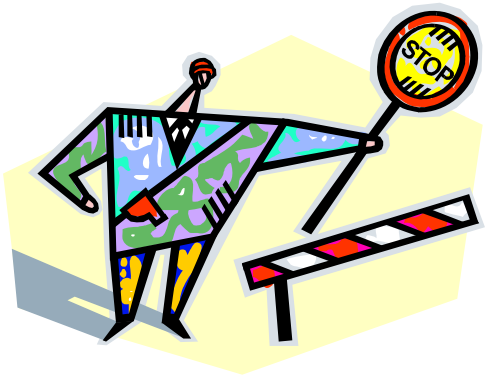
- Most insurance companies have case managers who can work with those who have special health care needs. Ask for their help if needed. Their role is to help you get the services and resources you need through your insurance company.

- Keep good records including bills, receipts and letters from your health care insurer. Document all your phone calls, faxes, and e-mails. Be sure to include the name of the person you talked with.

- Insurance companies don't pay unless something is "**medically necessary"**. Tell your doctor or other health care professionals why you need a medication, service, or equipment so they have a clear picture of what is needed and why it makes a difference in your health and quality of life.

- When a benefit is denied, always appeal. Seek assistance from doctors, nurses, teachers, counselors or others. Make your appeal personal. Help others see the benefit of getting what you want. Don't take no for an answer!

- Find ways to pay if your insurance doesn't. "Negotiate" the price. Plan a payment schedule. Ask your doctor, clinic, public health department, or hospital about Patient Financial Assistance Programs. Explore special community, church, or non-profit organizations that might help you pay. Find an advocate to help you figure things out.



What to Do if you Find Yourself Without Insurance

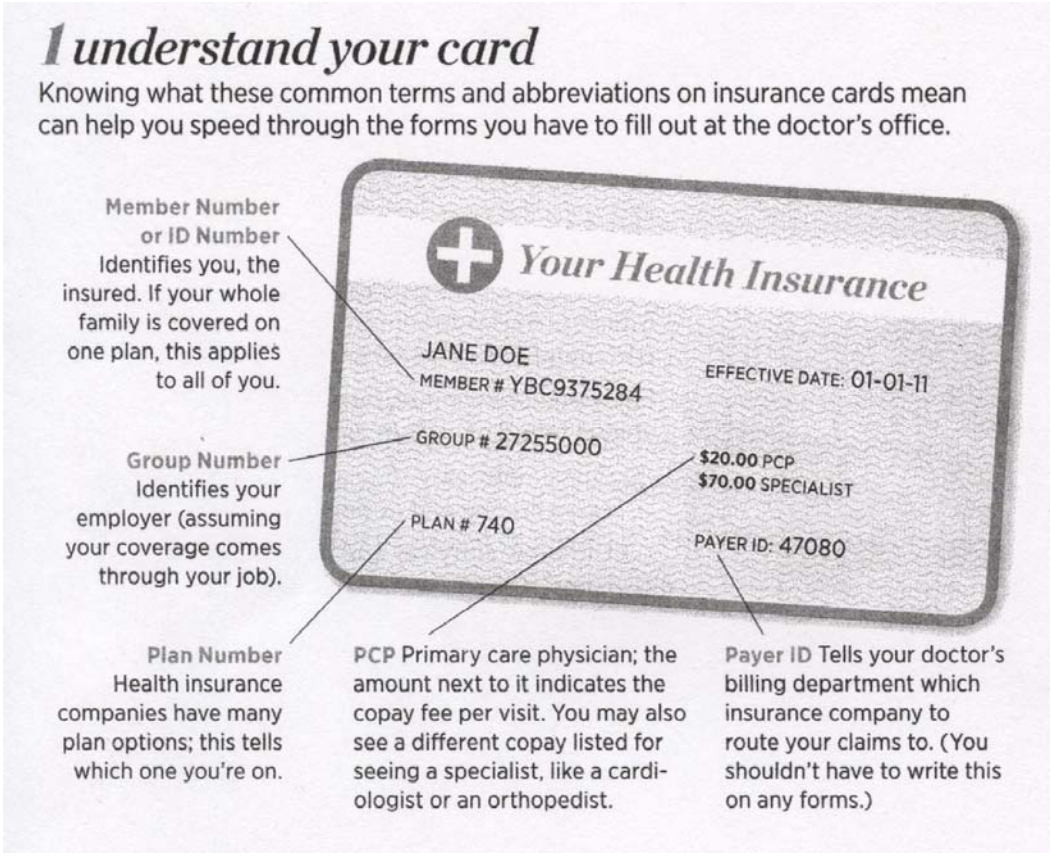
First, do not neglect your health care needs if you lose your insurance. There are resources out there, but you sometimes have to dig to find them. Second, talk with a social worker, care coordinator, or advocate who knows the resources in your area. They can help you find public clinics that provide free health care or use a sliding scale based on income, such as the local health department and federally funded primary care centers.

Churches, the Salvation Army, or other private organizations provide free health clinics in some communities.

Some children's hospitals can treat children up age 21 regardless of their insurance status. Examples include Shriners Hospitals for Children and St. Jude Children's Research Hospital. The important thing is DON'T GIVE UP even if finding resources is hard.

Transition Activities:

- Look at this insurance card. Then look at ***your*** insurance card. Find the member number or ID number, the group number, the plan number, the co-pays per visit, and the payer ID.



- Learn more about the insurance you have now. Will this change when you are 18?

- How will you pay for health care when you turn 18? Consider:

  - Can you stay on your family's plan? How long? (If your parents have jobs with insurance this may be your best option.)

  - Does staying in school affect your insurance?

  - Can you get student health insurance and/or health services at your college or technical school? How much will it cost, and what will it cover?

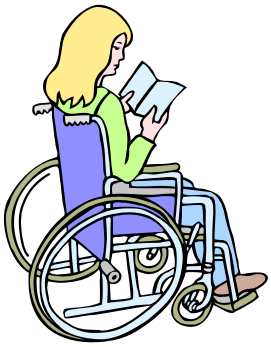
  - If you have a job, can you get health insurance through your work? How much will it cost, and what will it cover?

  - If you are receiving Medicaid, will it continue?

  - What will happen to Medicaid if you lose SSI?

  - If you are not on SSI, will you be eligible at age 18? Will getting on SSI make you eligible for Medicaid?

  - Do you need to consider getting Medicaid Waiver Services? What waivers are available in your state? Who is eligible?



Chapter 3:
Getting Ready for the Trip:
Staying in High School

What kind of work do I want to do?

How will I get the education and training I need to do what I want to do?

What volunteer work can I do to learn work skills?

How can my high school help me get ready for adulthood?

First of all, stay in school! You probably know how important it is to stay in school. Sometimes when tests and homework are staring you in the face, it's tempting to consider giving up and dropping out of school.

Do you know that high school graduates, on the average, earn over $7,000 more per year than high school dropouts? If you want to have a good life after high school (for example, have a good job, have a car, pay rent or own a house, be able to take vacations), you are much more likely to get it if you stay in school and get your high school diploma. Take full advantage of the time and opportunities you have in school to help you get the life you want after high school!

If for some reason you don't finish high school, get your GED (Test of General Educational Development). Contact your local or state adult education department for information in your state. See ***Resources for Roadblocks***, Chapter 3, for more ideas.

What would you like to do after high school? What classes should you take that might help you make the move from student to adult? As you develop your transition plan, think about:

- the courses that you, your parents, and teachers feel you should take
- what real life experiences you would like to have
- what out-of-school activities you might like to try

There are many experiences your school can set up, but you have to know what you're interested in and ***you have to ask***. These activities will help you get the knowledge and skills you need to map your life and reach your goals after high school.

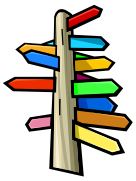
Transition Activity:

- Think about what you want to do in the future.

  Do you want to be a nurse, social worker or therapist? See if your teachers can arrange for you to job shadow for a day.

  Always thought you'd like to work with computers? Ask your teacher or guidance counselor about job opportunities in this area.

  Want to work on cars? See if auto mechanics is available in your high school or get a part-time job at a local garage.



Directions from your School

Your school's role is to help you develop and put into action a plan to achieve your hopes and dreams after high school. Some students with chronic health conditions or disabilities will be in regular education classrooms and others will receive special education services. If you receive special education services, you may choose to stay in high school until you are 21 to prepare for adult life

Special Education: If you are receiving special education services, federal law states that your **Individualized Education Program (IEP)** must include transition planning. By age 14, your IEP should include the classes, accommodations, and activities you will need to reach your post-graduation goals. You may be interested in technical training or work experiences. If you are college-bound, you should take more advanced classes. Be sure that you make your goals clear at your IEP meetings.

By age 16, schools must start putting your IEP transition plan into action. It should include specific types of instruction, community experiences, work, and adult living skills, as well as resources and services needed.

Research shows that *less than 50% of IEPs* include medical services, housing and transportation issues, independent living goals, accommodations and supports, or recreation and leisure. ***You have to ask to have these included!*** Be a self-advocate in IEP meetings…explain what you want to do and ask your team what resources are available to help you get there.

Regular Education: Many students with chronic health conditions or disabilities are in regular classrooms but need special accommodations or supports. Section 504 ensures that students with disabilities have equal access to an education. To qualify for services, the student must have a physical or mental impairment that limits one or more major life activities such as walking, eating, breathing, hearing, seeing, or talking. If the

student qualifies, a **504 Plan** will be developed and should include supports needed to be successful at school. In a 504 Plan, transition services are not required by law. ***Parents and students must request that transition planning be included.***

Regardless of whether you have an IEP or 504 Plan, it is important to start transition planning early. The following **Transition Timeline** can serve as a reminder of what needs to be discussed and when.

Transition Timeline

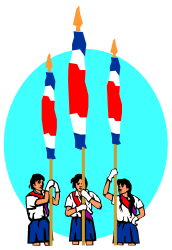
By Age 14 at home and in school:

- ✓ Think about what you might want to do in your future. This will affect what classes you should take in high school
- ✓ Learn good study habits and get good grades. Get help from friends, teachers, tutors or counselors if you are having trouble
- ✓ Read newspapers, magazines, books and on-line articles
- ✓ Practice writing in letters, e-mails, and a personal journal
- ✓ Use numbers in everyday life – count miles travelled, double recipes, subtract coupon values from prices
- ✓ Learn about other parts of your state, country, and the world
- ✓ Learn about how a car and other machines work
- ✓ Get involved in school and community activities
- ✓ With your family and friends, visit workplaces and volunteer - these experiences help you learn about what you might like to do

- ✓ Learn how to get around in your community. Be able to tell someone where you want to go. Learn how to read street and road signs and maps. If there are buses or trains, learn to use them.
- ✓ Learn to manage money
- ✓ Learn to use a computer – word processing, searching the internet

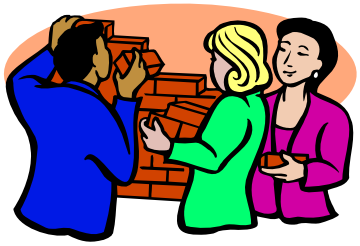
At age 14 with your school:

- ✓ Talk with your IEP or 504 Plan Transition Team about your current plans for life after high school. Ask for a meeting (if your school does not). An individual learning plan, graduation plan, or transition plan is started at age 14. The complete transition plan is not usually developed until age 16.
- ✓ The transition plan will include the classes you should take to help you reach your goals after school.
- ✓ Be clear about wanting a high school diploma at graduation and if you plan to go to college.



No later than age 16 or about 10th grade:

- ✓ More services should be included on your transition plan, such as: special skill, interest and vocational evaluations; instruction; community experiences; development of employment plans and independent living skills
- ✓ Attend transition fairs
- ✓ Identify job interests and abilities
- ✓ Include activities such as career exploration, job try-outs, job training, getting around the community
- ✓ Identify community services that provide job training and placement and learn adult skills
- ✓ Participate in volunteer experiences and think about summer employment
- ✓ Begin application to adult service agencies; they may have waiting lists you want to get on



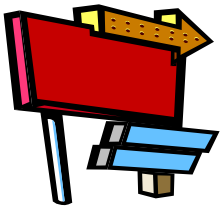
Between ages 16 and 21: Depending on individual needs, some students receiving special education may remain in school and continue working on transition goals until age 21. Update your transition plans every year.

- ✓ Contact *adult* service programs such as
  - o Medical and health care services and payment sources
  - o Colleges, vocational or technical schools
  - o Social Security Administration
  - o Centers for Independent Living
  - o Transportation and housing
  - o Recreation and leisure activities
- ✓ Continue to review and update your transition plan
- ✓ If going to college, take the ACT and/or SAT tests and Advanced Placement (AP) exams
- ✓ If going to college, go to College Fairs, visit colleges and their Disability Services offices
- ✓ If going to college, register with the Disability Service Office of your preferred school the semester before you begin so they can prepare your accommodations
- ✓ Be informed at least by age 17 of your rights as an adult that will transfer to you upon reaching legal adulthood (age of majority – usually 18)
- ✓ Be sure to check in with the Social Security office six months before turning 18 to see if you can keep benefits or get them as an adult
- ✓ If needed, families should look at long-term financial support planning, estate planning, guardianship, conservatorship, health care surrogate

Planning your IEP or 504 Plan Transition Meeting

At your IEP or 504 Plan transition meeting, you want to be ready to tell others about your hopes, dreams and goals. You also need to be able to talk about the steps you think you will need to take to reach your goals. Examples of goals for different people might include:

- I would like to graduate from high school and go to college
- I would like to learn a trade in high school and go to work
- I would like to be a volunteer and help people in my community
- I would like to get involved in a day program where I get to meet lots of people and do interesting things.
- I'm not sure what I want to do after high school, so my goal is to come up with a plan.



To make sure you are prepared for your transition meeting, look at the check list below. If you answer **no** to any of these questions ask your family members, teachers or counselor to help you.

√ Do I understand what transition planning is?
√ Has someone at school told to me how this all works in terms of IEP or 504 transition planning?
√ Have I received and reviewed a transition planning book or student survey for transition planning?
√ Have I received a copy of my Student Rights in regard to transition planning? (not required for 504 Plan students)
√ Have I thought about what my dreams for the future are?
√ Have I thought about how I will share my hopes, dreams, and what I am thinking about doing?

- √ Do I have information about my grades and my test scores (such as ACT or SAT or vocational abilities tests)?
- √ Have I been given the chance to invite people of my choice to my transition planning meeting? Your transition team can include your teachers, social workers, nurses, care coordinators, counselors, therapists, family members and others you think will help you with planning for your future.
- √ Do I know what accommodations I need?
- √ Am I ready to lead my IEP or 504 meeting?

Accommodations

Accommodations make your school work easier so you can be more successful. Accommodations are changes to the environment or the way you do a task that would allow you to participate in an activity. During your IEP or 504 meeting, ask for accommodations you think you need. Accommodations may be for medical or educational reasons and may involve use of assistive technology.

Transition Activities:

- Think about accommodations and assistive technology you might ask for. Check the ones that you think would be helpful.

  What medical accommodations do you need?

  - ☐ A bathroom you can get in and out of easily
  - ☐ Snacks and fluids to keep you well
  - ☐ Medications
  - ☐ Rest periods
  - ☐ Therapies
  - ☐ An aide to help with health needs and/or personal care
  - ☐ Other?

  What classroom accommodations do you need?

  - ☐ An aide to help with classroom learning activities
  - ☐ Note taking help, such as a tape recorder, computer, teacher's notes, another student's notes, or have a note-taker in the class
  - ☐ Test taking help, such as more time for tests, taking tests in a quiet area, having tests read to you, or taking the tests orally
  - ☐ Seating in front of class
  - ☐ More time to get from class to class
  - ☐ More time to complete tasks
  - ☐ Different ways to show abilities
  - ☐ Textbooks-on-tape
  - ☐ An extra set of books for home
  - ☐ Breaking up long tasks into shorter tasks
  - ☐ Ramps or other changes in the building that will allow you to get around
  - ☐ Bigger font on assignments
  - ☐ Use of notes/textbook for quizzes or use of a dictionary
  - ☐ Other?

What assistive technology will help you be more independent at school and in your future workplaces?

- ☐ Adaptive grips for pencils, spoons, cups
- ☐ Adapted computer with special keyboards or voice activation to improve speed or accuracy
- ☐ Communication devises to help others understand you better
- ☐ Wheel chair or walker that would increase your mobility
- ☐ Other?

- Find the Technology Center in your state. Technology Centers can help you with a technology assessment and offer equipment demonstrations, loans, and payment programs. "Google" technology center + disability + your state to find your nearest Technology Center.

- Would a service animal help you? Check out the possibilities.

In Chapter 5 of ***Resources for Roadblocks*** you can helpful websites on accommodations, assistive technology, and service animals.

Leading your Transition Meeting

Now that you have reviewed the checklist and considered the accommodations or assistive technology that you will need, are you ready to lead your transition meeting? If so, here are some tips that will help you be successful.

- Look your best and come to the meeting early
- Begin your meeting by stating the purpose
- Introduce everyone
- Go over your goals for the year and for the future
- Talk about the help you will need to reach your goals, such as accommodations and changes to the classes
- Ask for thoughts and ideas from your transition team
- Ask questions if you don't understand
- Work through differences in opinion
- Review what has been decided at the meeting: goals, steps to reach goals, and who is helping reach the goals in the stated timelines
- Talk about who will complete forms and paperwork
- Close your meeting by thanking everyone

Resources for Roadblocks, Chapter 3, can help you plan for your transition during high school.

Transition Activities:

- Look at the goals you set in Chapter 1. Are these still important to you? What else do you want to do? Who can help you?

- Get a copy of your current IEP or 504 Plan. Does it include everything you think it should: school, work, health, housing, transportation, needed supports, accommodations, and resources?

- Start planning now for your next IEP or 504 Plan meeting. At the end of this book is a questionnaire summarizing transition topics. You can use it to plan with your teachers and Transition Team. **You have the right to call a meeting anytime you think it will be helpful**.

- Practice what you want to say in your IEP/504 meeting.

- If you feel ready to lead your transition meeting, role play doing that with your family and friends.

Your Individual Education Program (IEP) or 504 Plan is meant to change and grow as you do. Make sure you have a copy of these documents and that you, your family and teachers refer to them several times during the school year. If something you agreed on is not happening, ask why? Be persistent! Teachers have lots to do, and they appreciate it when students remind them of what needs to be done.

Laws that Affect Your Education

Individuals with Disabilities Education Act (IDEA - Public Law 101-476)

IDEA requires schools to provide all students with a free education that is appropriate for the student and provided in the best environment. This might mean you take all general classes but go to a resource room for special help, or it might mean that you receive all instruction in general classrooms. IDEA serves students from ages 3 to 21 and requires transition services. School services under IDEA are something that every student with a disability is ***entitled*** to. This means that no matter who you are, what your income or your family's income is, or what kind of disability you have, the school is required to provide a free, appropriate education.

You are only entitled to these services, however, while you are still in school, typically until age 18 to 21. When you leave school you must be ***eligible*** in order to receive services that may help you (meaning that you must meet income or disability criteria, and you have to apply for them).

Section 504 of the Rehabilitation Act (Public Law 93-112)

This act states that no individuals with disabilities should be excluded from participating in activities, denied benefits, or be subject to discrimination under any programs or activities that receive federal financial assistance. Some of the requirements include:

- Providing reasonable accommodation for individuals with disabilities including school children
- Program accessibility
- Effective communication with people who have hearing or vision loss
- Accessible new construction and alterations

Family Educational Rights and Privacy Act (FERPA or the Buckley Amendment)

FERPA grants four rights. If you are under age 18, your parents have these rights. Once you reach the age of 18, and if your parents do not have guardianship, these rights are transferred to you.

- See the information that the school is keeping on you
- Seek amendment to those records, and in certain cases, add to the record if you do not agree with them
- Consent to the disclosure of your records so others may see them
- File a complaint with the FERPA Office in Washington, D.C.

Chapter 4:
Abiding by the Laws: Becoming an Adult at Age 18

What are my rights and responsibilities when I become a legal adult at age 18?

At age 18 you become a legal adult! You can make your own decisions and you are responsible for them. An important part of planning for transition is learning about your rights and responsibilities as an adult so you can enjoy your new legal status and avoid costly mistakes.

What are your rights as an adult?

In most states, when you reach 18, you are given all the rights of an adult (except drinking alcohol). These include the right to:

- Be completely independent of parental control
- Vote in federal, state, and local elections
- Sign a contract (rent an apartment, buy a car, take out a loan) in your own name
- Obtain medical treatment without parental consent
- Enlist in the armed forces without parental consent
- Marry without your parents' permission
- Apply for credit in your own name
- Make a will and power of attorney
- Make your own end-of-life decisions (living will)
- Be an organ donor by indicating your wishes when you renew your drivers' license
- Obtain identification and documents without parental consent or involvement

At age 18, you make your own decisions about education plans. You can:

- Ask for and participate in IEP and 504 Plan meetings without your parents.
- Request re-evaluation and changes
- Request a " mediation" or " due process" hearing if you do not believe you are getting the services outlined on you IEP
- Drop out of school without parental consent

What are some of your new responsibilities?

- Your parents are no longer legally responsible for you or required to support you
- You can be held to a contract
- You can be sued
- You are legally responsible for your own actions
- You can be tried as an adult if you are accused of a crime
- You can be called to serve on a jury
- You must register with the Selective Service (draft) within 30 days of becoming 18 if you are male.

Assuming Adult Responsibilities

Because your parents can no longer make legal or health decisions for you, it will be important to consider who you would want to speak for you if you lose your ability to speak for yourself. You may want someone to help you with certain areas of adult responsibilities. The following legal options should be discussed:

A **Durable Power of Attorney is often the most important legal document a person can have**. It allows another person to handle medical, banking, other financial and legal affairs. If you do not have a valid Durable Power of Attorney and lose mental or physical abilities for an extended period of time, your family will be forced to obtain guardianship over you, a complex and often unpleasant process.

If you do not want to consider a power of attorney, you may want to consider appointing a **Health Care Surrogate**. This is an adult who is appointed to make healthcare decisions for you when you become unable to make them for yourself. The Health Care Surrogate cannot override your wishes. His or her sole role is to speak for you when you can no longer communicate with your doctor.

A Living Will is a written statement directing your doctor or other health care providers to withhold treatments that prolong death when death is inevitable.

The internet will provide more detail about these legal documents and state-specific information. Often forms can be down-loaded for free and completed by adults. Your signature on these forms must be witnessed, usually by a notary public. You can get help from your state Disability Rights or Protection and Advocacy organizations or The Arc. See ***Resources for Roadblocks***, Chapter 4, or "google" these resources.

Transition Activities:

- What surprised you about your adult rights and responsibilities when you read the list? What kind of help do you want and need to meet your responsibilities?

- Download a copy of your state's living will or health care surrogate forms from the internet and complete it. Everyone over the age of 18 should have a living will and appoint a health care surrogate. Consider: Who do you want to make health care decisions if you cannot speak for yourself? What kind of life-prolonging treatments do you want to have or refuse? What are your wishes regarding organ donation?

Information for Families

Some young people may not be able to recognize when a decision needs to be made, consider possible options, let others know their wishes, take care of their personal needs, or recognize the consequences of their decisions without additional support. For these young people, guardianship (or in some states and situations, conservatorship) may be appropriate.

Guardianship is a legal tool that grants a parent or other adult the legal authority to make decisions for a legally disabled adult. An adult is considered to be legally disabled (a ward) if a court, after a jury trial, has ruled in a disability hearing that the person cannot take care of his or her personal needs or manage finances. At the same time the court declares a person to be disabled, it appoints a **guardian** for personal needs and in some states, a **conservator** for financial needs, to help in the areas the disabled person cannot manage alone. A guardian may be a friend or family member who is willing to care for the disabled individual. A conservator has experience managing financial matters.

Guardianship severely limits an individual's right to make independent decisions and should only be considered when there is no less restrictive alternative. When in doubt, leave the option open for the young person. Partial guardianship is an alternative that allows the young person to make many of his or her own decisions with family members or guardians assisting only in areas where there is need. States vary in guardianship laws. Check with your state Protection and Advocacy (P&A) agency or other websites in ***Resources for Roadblocks*** for Chapter 4.

Estate planning is another important part of transition planning for parents of young people with special health care needs. Often well-meaning parents and friends of the family put aside money in the name of the person who is disabled. This money could make the person ineligible to receive any benefits, such as SSI or Medicaid.

Families should work with a knowledgeable lawyer to set up a special needs trust. Some lawyers may have experiences with trusts but may not have worked with establishing trusts that protect needed benefits. It could be worth thousands of dollars to your young person to get the right help. Get good information, consult with families who have been successful, interview lawyers carefully, and don't be afraid to get a second opinion. See ***Resources for Roadblocks,*** Chapter 4, for additional information.

Laws Giving Rights to People with Disabilities

Americans with Disabilities Act (ADA - 1990):

- Requires equal access for people with disabilities to communications, public transportation, and buildings that are used by the general public, such as hotels, restaurants, retail stores, and doctor's offices.
- Employers must provide reasonable accommodations for their employees with disabilities, unless undue hardship would result.
- Employers may not discriminate, and many are learning to use job coaches and make accommodations to aid persons with disabilities to become successful workers.
- Housing and transportation must be accessible for all people with disabilities.
- The chance to live, work, and play in the same places as non-disabled individuals in the community (with their family and friends) is the promise these laws bring to all persons with disabilities.

The Olmstead Decision (1999):

- Requires states to provide their services, programs, and activities "in the most integrated setting appropriate to the needs of qualified individuals with disabilities."
- "Integrated setting" means that services, programs, and activities should occur in environments that consist mostly of people without disabilities.

Chapter 5:
Hitting the Highway: Working

What kind of work do I want to do?

What training and experience do I need to do it?

In today's world with rapidly changing job markets most people change jobs, or even types of work, several times during their lives. During high school you can learn the skills you need to work in a variety of jobs.

Why work?

- Work brings meaning and purpose to your life, especially if you enjoy your job!
- Work helps you get out and meet new people.
- Working, even at minimum wage, pays almost twice as much as SSI. Social Security alone is not enough to live comfortably.

Rarely does a young person get the job he or she wants on the first try. Often it takes more time and effort than you think to get a first job, but it is usually easier to get a second job if you have a good work history.

Hopefully during high school you developed job skills that will help you get the job you want. If not, then job preparation and training may be a first step. Some jobs offer on-the-job training. If you are in a program that helps you find work, a job coach may work with you as you learn what you need to do the job. Other jobs may require more schooling.

You may need some changes in your workplace, such as a ramp into the building or support bars in a restroom, or assistive technology, such as voice-activated computer software. The Americans with Disabilities Act (ADA) says employers must offer reasonable accommodations. Practice asking for what you need while you are in school.

A reasonable accommodation is any change or adjustment to a job or the work environment or way that things are usually done that would allow you to apply for or perform job functions or have equal access to benefits available to other individuals in the workplace.

Types of Employment

Competitive employment is a full-time or part-time job that you are able to get, and keep, "on your own". You don't need help in completing job applications or going for interviews. You are able to learn the job through help provided only by the employer.

Self Employment is work that you create and do. For example, some youth may wish to start a small business such as lawn care, pet sitting, web design or selling cosmetics, books, or products on e-Bay. Other youth are talented artists and craftspeople. Government loans and help from Vocational Rehabilitation are available to help young people with disabilities get started in their own businesses. Be creative as you think about your interests, talents and opportunities!

Supported Employment is when you need help in getting and/or keeping a competitive job. The goal is to help persons with disabilities get a job and be successful. Help might be given in:

- discovering personal gifts and interests
- exploring types of work you might not have thought about
- applying and interviewing for a job

- learning the work routine and specific work skills
- asking for accommodations and using assistive technology
- working out the job and its tasks with an employer
- getting along with co-workers
- job coaching

To find supported employment resources in your state "google" supported employment + your state.

Sheltered employment refers to a place operated by an agency that (except for staff) employs only disabled persons at minimum wage.

Volunteer Work is unpaid work where you can follow interests, help others, and get experience that may help you get a job in the future. Through volunteer work you may meet new people, make friends and get references for future jobs. You can practice working and learn what you like and don't like about different jobs. Volunteer work looks great on a resume and on college applications.

Tips for Getting a Job

- Read about interesting careers
- Talk with people doing what you would like to do
- Do career testing at school to learn about your skills and interest areas
- Include job training in your transition plan
- Get the training you need to learn how to do the job
- Develop a resume
- Read job ads on the internet or in the newspaper
- Apply for a number of jobs in your area of interest – you can always turn down one if you are offered more than one job!
- Learn to apply for jobs on-line – if you don't have a computer, you may do this at the library

- Let your parents, teachers, friends' parents, relatives and neighbors know you are looking for a job – they might know of jobs available or can give you a personal reference that will help you get an interview
- Follow through each job opportunity by completing the application and sending letters of reference. Call the employer and let him or her know you are very interested. Be persistent but be polite.
- Take volunteer opportunities - these often lead to work opportunities
- Keep track of who you have contacted and what they said. It may lead to a job opportunity in the future.
- Send a personal thank you card within 24 hours after an interview.

Tips for Keeping a Job

- Be on-time and responsible for your work and learning skills and routines
- Work with co-workers and supervisors
- Know when and how to talk about your disability
- Get assistive technology and accommodations to help you work better
- Stay healthy and know how and when to call in sick
- Plan medical and other appointments outside of work time

In ***Resources for Roadblocks***, Chapter 5, are websites that will help you to develop a resume and have a successful job interview.

Transition Activities:

- What kind of work would you like to do? What skills do you need to develop to do it? What education do you need?

- What work supports or accommodations might be helpful to you? Get information on those.

- Practice using the internet to do a job search.

Resources for Employment

Here are some programs that help you get and keep a job.

Vocational Rehabilitation (VR)

Every state has a Vocational Rehabilitation agency to help people with disabilities meet their work goals. This may include additional education or training, modifying a vehicle, or getting a computer.

A student may receive help from VR if he or she wants to work and:

1) Has a physical or mental impairment which is or results in a substantial impediment to employment. Many states with an "order of selection" serve the most severely disabled first. Less disabled people may only get information and referral.
2) Can benefit from VR services in terms of an *employment outcome.*
3) Requires VR services to prepare for, enter, engage in or retain gainful employment.

Youth who receive SSI as children are referred by the Social Security Administration to VR at age 16 because they are presumed to be eligible for VR services.

VR Services in your state may include:

- Determining eligibility and vocational needs
- Counseling and guidance
- Development of an Individual Plan for Employment (IPE)
- Funding for assistive technology or other equipment
- Funding for supplies
- Job placement, coaching and job maintenance services
- Vocational training or post secondary education (such as in-state tuition payments)
- Supported employment
- Personal assistance services
- Interpreter and note-taking services

- Car or van adaptations
- Funding for transportation
- Coordination of services to reach employment goals
- After-employment services to help you keep your job

Workforce Investment Act (WIA)

WIA has special programs and services to serve youth who may not be able to get help from Vocational Rehabilitation. Services you might ask for include: looking at your abilities and the things that may make working difficult for you, training and career counseling, internships and work experience, and information about different careers. "Google" agencies called One Stop Career Centers or Workforce Development + your state or contact your nearest Center for Independent Living.

Social Security Administration - SSI and SSDI

Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI) may provide you with the financial base you need as you enter the adult community. Both have special programs to allow persons with disabilities to be employed in their communities. The Social Security Administration defines a disability as a physical or mental problem that is expected to last at least a year or result in death and prevents a person from obtaining full employment.

Children who receive SSI must reapply for SSI at least one month before their 18th birthday. Eligibility criteria are stricter for adults. In most states, if you get SSI you also receive Medicaid. If not, you should apply for Medicaid separately.

If you work and pay into Social Security, and you become disabled, you may become eligible for SSDI. If either of your parents is disabled or either parent has died, you may be eligible for SSDI now under their work record.

If your parents are of retirement age and you are over 18 years of age, you may also be eligible for benefits if you meet the definition of disability for adults. After receiving SSDI for 24 months you are eligible to apply for Medicare.

Work Incentives: Some young people on SSI or SSDI worry about losing their Social Security checks and Medicaid or Medicare if they work. Work Incentives help people who get benefits from Social Security go to work by minimizing the risk of losing their benefits. Some incentives you might discuss with a Social Security or Center for Independent Living counselor include:

Ticket to Work: The Ticket to Work Program helps people with disabilities age 18 and over who want to work. A Ticket increases choices for obtaining employment, rehabilitation, and other support services needed to get or keep a job. SSDI and SSI disability recipients may receive a "Ticket" they can use to get services from a state vocational rehabilitation (VR) agency or another approved provider of their choice called "Employment Networks". Employment Networks (ENs) are private organizations or government agencies that have agreed to work with Social Security to provide employment services to SSI and SSDI beneficiaries with disabilities.

Examples of SSI or SSDI Work Incentives that change how your earnings are counted by the SSA are:

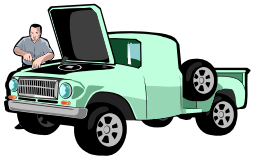
- *Student Earned Income Exclusion* allows SSI recipients under age 22 and attending school regularly to exclude a specific amount of income earned. It allows students to test their ability to work without any reduction in their SSI checks.

- *Plan to Achieve Self-Support* (PASS) allows individuals with disabilities to exclude income and/or resources needed to pay for employment-related services, equipment, and supports such as job development, job placement services, vocational evaluations, job coaching, basic living skills, personal care assistance, transportation, books, tuition, and assistive technology.

- *Impairment Related Work Expenses* (IRWE) allows the recipient to deduct from job earnings the cost of certain services needed to work including attendant care; medications, supplies and equipment; and work adaptations and equipment and special transportation.

- *1619A and 1619B* allow people with disabilities to keep part of their SSI or SSDI checks and Medicaid or Medicare when working.

- *Section 301*: *Continued Payment under a Vocational Rehabilitation Program or Similar Program* allows people on SSI or SSDI who improve medically and are no longer thought to be disabled by SSA (such as when recertified at age 18) to continue in their vocational rehabilitation, educational, work incentive or similar program and to continue benefits until participation in the program ends. SSA must look at the situation and decide that your continued participation in the program will increase the chance of your permanent removal from the disability benefit rolls.



For more information about work incentives and work opportunities, contact your Social Security Office, Vocational Rehabilitation Agency, Center for Independent Living, or school counselor, and see ***Resources for Roadblocks***, Chapter 5.

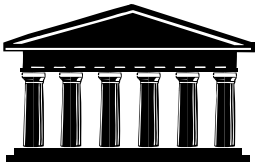
Transition Activities:

- Contact your local Vocational Rehabilitation office and make an appointment to talk with a counselor. Find out what services they can offer you. **A big heads up**…If you miss your appointment they will NOT call you. VR assumes that if you want their help you will be responsible for getting and keeping appointments and following up on the plan. There is no hand-holding.

- Learn more about Work Incentives that you might use by looking at the SSA website or talking with a Social Security counselor.

- It pays to work. Talk with someone at Social Security to see how employment income will affect your benefits.

Chapter 6:
Moving Toward Your Destination:
Continuing in School



Do I need more education to do what I want to do?

Where is the best place to get that education or training?

College is more than just an opportunity to learn. It can mean the difference between a low-paying job and a high-paying career. College graduates can expect to earn salaries double those of high school graduates. At college, you can explore and broaden your interests, gain skills, pursue your goals, meet people who become lifelong friends, and grow in ways you can only imagine now.

Which college is best for you? Visit schools that seem interesting and see if one is a good fit for you. See how you feel when you get on campus and meet with students and teachers. Go to sports, arts, or other campus activities while you are still in high school. Your choices depend on your interests, career goals and academic record. Some examples of "postsecondary education" include:

Technical School

Technical school can help you learn trades, such as carpentry, plumbing, auto mechanics, welding, office skills, child care, practical nursing or medical assistant, and graphic design. Courses may lead to certification or apprenticeships.

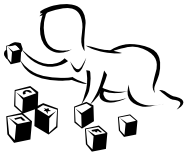
Community College (2-3 years)

Community colleges offer associate degree programs and pre-baccalaureate programs. Associate degrees take about two years to complete. Some programs include: early childhood education, nursing, dental hygiene, x-ray technician, computers, and many others.

Pre-baccalaureate programs are those that you start at a community college and complete at a four-year college or university. For example, you may decide that you want to be an engineer which requires a four to five-year baccalaureate degree. You could take your first two years of coursework at a community college and complete the remaining two to three years at a college or university.

Why go to a community or technical college instead of a university?

- Smaller classes, so you get more attention from your instructors
- Costs less than most four year colleges
- Takes less time to get a degree or diploma (usually 2 years or less)
- High employment rate for graduates
- Can transfer most credits to a 4-year university easily
- Some give free tuition to people receiving SSDI or SSI



College or University (4-6 years)

A college or university offers more specialized education in particular subjects, such as psychology, social work, fine arts, business administration, education, nursing, or pre-medicine or pre-law. At a college or university you can earn a baccalaureate degree and at some schools master's, doctoral and professional degrees.

Disability Services Coordinators

Each school has a Disability Services Coordinator - someone who can help you get the supports you may need if you have a disability. If you choose technical school or college, part of the transition plan is connecting with this person. Some schools are better than others, both academically and with support services. Talk with your guidance counselors, go to college fairs, and search the internet to find schools that meet your needs.

If you have a disability that affects learning, such as Down syndrome or autism, there may be programs available in your area to help you get into college. These are called Comprehensive Transition Programs (CTP). These programs arrange services and supports between colleges and outside resources (such as Medicaid Waiver programs, transportation, tutoring, etc.). Admissions policies of schools can be very different. For example, some schools will allow students to audit courses based on their interests and vocational desires. Others may require you to take a placement or entrance examination prior to admission.

Paying for College

Financial aid includes grants, scholarships, loans, and work-study programs. ***Your most important action is to apply for aid!*** Many scholarships are available for specific programs or types of students, including students with disabilities.

- Pell grants are available for qualified low-income students. This money **does not** have to be paid back unless you drop out of school.
- There are also loans available to parents and students. This money **does** have to be paid back with interest. Usually payment for student loans begins after graduation or when the student withdraws from school. It is important to figure out how much money you think you will make in the future and not get into debt that will be hard to pay back.

Other help for students with disabilities includes Vocational Rehabilitation, SSI, and special scholarships. VR may pay in-state tuition and assist with other resources. SSI has a disability scholarship, called a PASS Plan, for college-bound students. Every college-bound student who receives SSI should check out the PASS Program.

Students can "google" college scholarships + disabilities and find information on scholarships. Call the financial aid office of schools that interest you or ask your high school guidance counselor, VR or Social Security counselor for help in figuring out the best way to pay for college. Start in high school to explore all possible resources.

College costs a lot of money, and students and their families should be sure they are getting good value for their money. Check out graduation rates and employment rates of different schools and majors. Unfortunately, there are some schools that promise great jobs following graduation that do not have good records. Be careful about schools that have low entrance requirements, high tuition, and promise a high paying job upon graduation.

For additional information, such as the Free Application for Student Aid or "FAFSA" web-site, and scholarship information, see ***Resources for Roadblocks,*** Chapter 6.

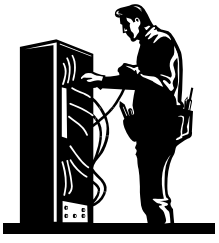
Transition Activities:

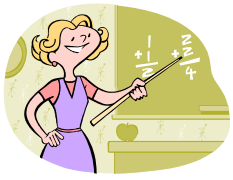
- Start planning for how you will pay for college. Are you eligible for a Pell Grant, VR, or SSI PASS program? What scholarships might be available to you? Will you or your parents need to take out a loan? What are deadlines for applications for financial aid?

- Print off a copy of the FAFSA and show it to your parents. They will need last year's income tax forms and other financial information to complete this.

How is college different from high school? Are you ready?

High School	College
Adults remind you of your responsibilities	You are responsible for your activities and the decisions you make. You must recognize the need for help and arrange for it.
You are usually told what to do and corrected if you're out of line.	You are not told what to do and you must accept the consequences of what you do.
Grades are usually given for homework	Grades are usually given only for tests and major projects. Students are responsible for monitoring their own progress.
Time is usually structured by others.	You manage your own time.
Classes are arranged for you and are on a set schedule.	You create your own schedule. Classes meet less often. Try to plan your schedule with things like stamina and medication side effects in mind. Think about when you learn best – morning, afternoon or evening.
Classroom accommodations are taken care of by your IEP or 504 Plan team.	You must find the Disability Services Office, disclose your disability, and arrange for classroom accommodations.
Assignments are usually short, reviewed, and taught more than once	You will have much more reading to do and assignments will not necessarily be reviewed. Papers and essay questions are common assignments and evaluation methods.
Classmates are the same age.	Classmates include people of all ages.
Class sizes are fairly similar	Classes may be very small or very large
Teachers are available every day	Less contact with instructors and less feedback available for information presented at a faster pace.





What to Look at When Choosing a College

Type of institution: Do you want to attend a vocational or technical school, community college, or a four-year college or university? Does this college offer the field you would like to major in? If you have not decided on a major, does the college offer a variety of choices?

Location: Do you want to move away from home; if so how far? Would you like to live in a small town or urban area? What type of climate and weather do you prefer? If you use a wheelchair, do you want a campus that is flat? How will you get to and from campus?

Size of the college and the classes: Would you like to know everyone on campus or would you like to be known by your student number? Are you more comfortable in a class with a small number of students or a class with about 250 students? What is the campus like in terms of social activities and level of student activity on campus?

Academic standards: What are the GPA and ACT/SAT requirements?

Cost and financial aid availability: What does it cost to attend this school each year? What is the financial aid package the school is offering, and how much will you have to pay beyond that? You will need money for tuition, books, fees, school supplies, transportation, and other miscellaneous items (movies, laundry, the phone bill, and, if you're lucky, the occasional date!) and room and board if you choose not to live at home.

Disability services: Is the campus accessible and barrier free? Are there services that assist people with disabilities? Are people with disabilities able to participate in extracurricular and social activities?

Tips for Using Disability Services

Apply early. Visit the disability services office no later than one semester before you will start classes. Section 504 of the Rehabilitation Act requires that you receive accommodations planned for you – *but you must ask for them!*

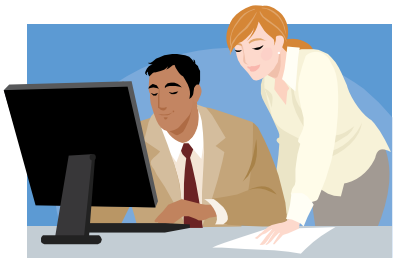
Follow documentation guidelines. Bring proof of your disability from your medical doctor, psychiatrist or psychologist so the services and supports you need will be ready for you on the first day of classes. Explain how your health condition may affect you during the semester so professors and staff know how they can help.

Make sure your equipment works properly. Each year have your wheelchair checked or have your laptop or software updated. Learn how to fix minor problems.

Talk to your professors if you have problems in class. Try to see them during scheduled office hours or make an appointment.

Get to know the head of the Disability Services office. See your disability services counselor once a week to make sure you receive your planned services to avoid problems.

Get to know the student health service. Learn where student health is located, contact information, services are available, and referral services so if you have a health issue or crisis, you know what to do.



Is College Right for You at this Time?

College is not for everyone and going to college right after high school is not always the best plan. It takes courage and maturity to decide what is best for you as illustrated in these stories.

> John, now 22, was studying industrial engineering in college. Halfway through the first year, he decided school just wasn't working out, although he stayed for the full year. He is now an in an apprenticeship program to become an electrician. "Sometimes you feel that society says you have to go to college" says John. "But I knew I had to figure out what was right for me. And now that I have, I don't regret my choice at all."
>
> Ava, now 23, is a freshman in college. She has worked several jobs since graduating from high school. One of her jobs was in a day care center. Working with young children helped her decide to pursue a college degree in early childhood education.

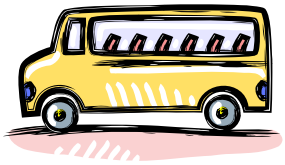
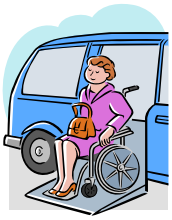
Go after your dreams! Find your own right path and follow it!

Transition Activities:

- Look for a college that has what you want in a school, such as academic programs, size and location, cost, and disability services. What are deadlines for application? What are admission requirements? Do you meet them?

- Make a list of your activities, work and volunteer experience, accomplishments, honors and awards that you might put on a college application.

Chapter 7:
Cars, Buses, Trains, Planes, Boats: Transportation

How will I get around after I graduate from high school?

Getting where you need to be when you need to be there is necessary for adult responsibilities. Transportation may be the deciding factor for where you live, work, go to technical school or college, and spend your free time.

There are lots of types of public transportation, such as city bus, subway, train, or special van for people with disabilities, but not all are available everywhere. You can "google" transportation + disabled + your city and state to find what is available in your area. If you receive Medicaid, it will pay for transportation to a medical appointment in most states.

It is important to explore what your transportation needs will be and check to see what your options are. For example, if you need public transportation to go to work, be sure that the bus or train runs during your working hours. If you need to use special transportation services for persons with disabilities, check to see if the service can get you to work or school on time. You can also think about walking, biking, wheeling your wheel chair, or catching a ride with friends or family.

Many people with disabilities rely on friends and family for rides. Some decide to buy their own vehicles. Buying your own car or van costs a lot of money. There are no federal programs that assist with purchasing a vehicle; however, some states have low interest loans to help persons with disabilities. Vocational Rehabilitation will pay for modifications of a car or van that is needed for employment. See ***Resources for Roadblocks***, Chapter 7, for other sources of help.

Also important is learning the skills needed to safely get from one place to another, sometimes called “navigation skills”.

Can you cross streets safely?
Do you know the rules of the road for safe bike-riding or driving?
Can you read maps and recognize landmarks?
Can you read street signs?
Can you find stops for the bus, subway, or train?
Can you pay fares and talk with bus drivers and other passengers?
Do you know what to do in case of emergency or disaster?

Transition Activities:

- Think about different things you have to do or want to do. How will you get there? What kinds of transportation are available? How can you learn to use them? How will you pay for them?

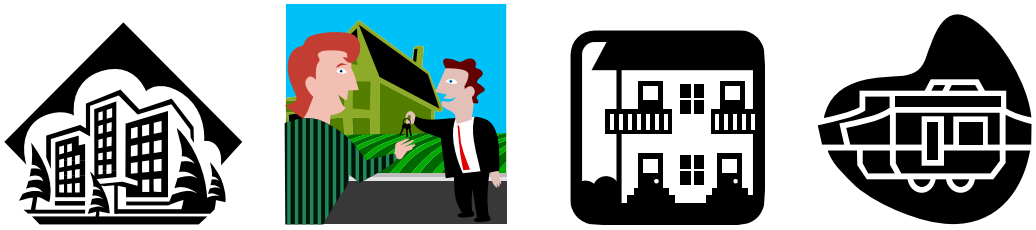
- How will transportation affect the decisions you make about where to live, work, go to school, play, and participate in a faith community?

- Is driving a car or van realistic physically and financially? What do you need to do to get a drivers’ license? How will you pay for and adapt a vehicle? How will you pay for gas, maintenance, repairs, and insurance?

- Ask to have driver’s training to learn rules of the road and navigation skills included in your IEP or 504 Plan. The classroom section will help you learn navigation skills even if actual driving is not possible.

- Contact Vocational Rehabilitation and ask about a driving assessment and information about vehicle modifications.

Chapter 8:
Lodging Along the Way: Housing



Where will I live after I graduate from high school?

You may continue to live in your family's home for a while until you are earning enough money to rent your own apartment or one that you will share with a roommate. You may be going on to college and will be living in a dormitory. You may live independently or with supports.

Independent Living is when you are able to live "on your own" with little or no support. You are able to care for your personal needs related to grooming and dressing. You are able to cook, clean, shop, and do your own laundry. You pay your own bills. You can take care of routine maintenance around your home. You are able to travel between your home and your work place on your own.

Supported Living is living on your own but with some help with selected tasks or activities of daily living. You may need someone to help you get ready for school or work. You may need help with housekeeping, shopping or cooking. These "supports" make it possible to live on your own. Figuring out the best option for supported living in your state and community can be challenging. Resources vary for those with physical and intellectual disabilities and from state to state.

Personal Care Attendants

Some young people need a personal care attendant while going to college or during their work day. Some may choose to have a personal care attendant as a part of their supported living plan. Funding for a personal care attendant can be through personal or family funds or through a state sponsored program such as Medicaid or Vocational Rehabilitation. Eligibility varies state to state. Ask members of your transition team to help you find resources in your state or community.

Medicaid Waivers: Persons with physical disabilities that impair independent functioning often qualify for support services through a Medicaid waiver. The goal of these waivers is to enable persons with disabilities to live with help at home rather than go to a facility, such as a nursing home. There are restrictions on income and level of disability.

Check what waivers are active in your state. "Google" Medicaid Waivers + your state and be sure the web page you are looking at has current information. Also " google" supports for community living and/or supported living + your state. Many programs have waiting lists so apply early and get on waiting lists. Because resources change rapidly and states vary in what they provide, talk with a member of your transition team who knows about the supported living options in your state.

Paying for Housing

Regardless of whether you live independently or with supports, one big challenge for young people moving out on their own is paying the rent. Section 8 housing is the government's main program for assisting very low-income families, the elderly and disabled to afford decent, safe housing in the private market. There may be other rent subsidy programs available in your local area. Contact your nearest HUD office or local Public Housing Authority about Section 8 and other public or private rent assistance programs. There are often waiting lists, so start planning early and get on the list. For resources in your area "goggle" Section 8 + your city or county OR rent assistance + your city or county.

Centers for Independent Living (CILs)

Centers for Independent Living help people with disabilities live more fully in their communities. They serve people with all kinds of disabilities – not just one group. However, all services may not be available everywhere.

Centers for Independent Living teach self-help skills, inform people about existing disability programs, and create new services to fill gaps. They can help you prepare to work. CILs maintain files on resources including listings of accessible housing. They can help you learn about transportation in your community and how to use it. CILs can help you complete the applications for Assistive Technology programs in your state.

Other Resources:

Other possibilities for supported living assistance include: Volunteers of America, Home Health Agencies, and state departments for Aging and Developmental Disabilities.

See ***Resources for Roadblocks***, Chapter 8, for additional resources on supported living, Medicaid waivers, personal care attendants and housing.

Transition Activities:

- Do you want to move out on your own or would it work best to live with family members while going to school or getting started with a job?

- Regardless of whether you move out or stay at home, what kinds of supports will you need to live as independently as possible?

- If you choose to move out, what do you want or need to make it work? Think about the following questions:

  - What can you afford in your budget for rent *and* utilities? In a good budget, you spend no more than 1/3 of your income on housing– so if you make $20,000 per year, housing should cost no more than about $6,500 per year or about $500 per month for rent *and* utilities.
  - Do you have money for deposits on rent and utilities?
  - Do you want to stay in an apartment, a house, or a trailer?
  - Do you want to have roommates?
  - What do you need to live happily (telephone, cable TV, dishwasher, internet access)? Can you afford these now?
  - Do you need special design features, such as wheelchair accessible doorways and bathrooms?
  - What kind of assistive technology or service animals will make it possible to live more independently?
  - Who can help you? Have you contacted resources such as a Center for Independent Living that can connect you with information, programs, and agencies to help with housing?

Chapter 9:
Paying for the Trip: Money Management

What will my income be?

How will I pay my bills?

How will I manage my money?

Becoming an adult means managing your money. Money management includes: earning money, opening and depositing money into bank accounts, paying bills on time, using debit and/or credit cards, and balancing your checking and savings accounts.

A good household budget starts with knowing how much income you have and then an honest listing of your monthly expenses. Housing and transportation take a large portion of a budget of young adults. It is difficult to have nutritious food and your cell phone and internet access if you spend a lot for housing and transportation.

You will have to make hard choices about what is most important because there is probably not enough money for everything you want! You will have to make sacrifices now to save money to have what you want in the future (for example, drinking water instead of buying a soda or coffee every day that costs $1 or more can help you at save $30 per month or $360 in a year) . Also, watch buying on credit – you pay interest and end up paying much more for what you buy.

Resources for Roadblocks, Chapter 9, will give you more information on money management.

Transition Activities:

- Write down everything you buy for one week. Do you see places to save money? (Hint: snack foods, fast foods and impulse buying can really "kick" your pocketbook!)

- Use the budget worksheet on the next page to list your income and all of your usual expenses in the categories. What income do you need to afford the things you want? Where can you cut expenses until your income goes up?

- Check with a local bank for advice on managing your money. They can help you with checking services or a pre-paid VISA card to help you stay out of debt.

- Talk with your family about paying "rent". The money can go into a savings account and you will learn to budget your money.

Monthly Budget

For: _____ Date: _____

INCOME

Take Home Pay $ _____
Allowance $ _____
Gifts $ _____
Part-time Jobs and Chores $ _____
Other Sources $ _____
TOTAL $ _____

EXPENSES:

FOOD

Groceries $ _____
Lunches and Snacks $ _____
Eating Out $ _____
TOTAL $ _____

TRANSPORTATION

Car Payment $ _____
Insurance $ _____
Gasoline $ _____
Maintenance and Repairs $ _____
Public Transportation $ _____
Other (parking, tolls) $ _____
TOTAL $ _____

HOUSEHOLD

Rent/Mortgage $ _____
Utilities (electric, gas, trash, water)
$ _____
Cable/Satellite TV and Internet
$ _____
Telephone and Long Distance
$ _____
Cell Phone $ _____
Other Household Expenses
$ _____
TOTAL $ _____

HEALTHCARE

Doctor $ _____
Dentist $ _____
Prescriptions $ _____
Medical Insurance $ _____
Other Healthcare Expenses $ _____
TOTAL $ _____

LOOKING GOOD

Clothes and Shoes $ _____
Toiletries $ _____
Laundry and Cleaners $ _____
Hair Care $ _____
Other Looking-Good Expenses
$ _____
TOTAL $ _____

JUST FOR FUN

Movies/Games/Concerts $ _____
Dates/Trips $ _____
Music Purchases $ _____
Books/Magazines/Newspaper
$ _____
Hobbies $ _____
Other $ _____
TOTAL $ _____

MISCELLANEOUS

Credit Card $ _____
Savings and Investments $ _____
Education (tuition, books, fees)
$ _____
Gifts and Charity $ _____
Pets $ _____
TOTAL $ _____

TOTAL ALL INCOME $ _____

Subtract –

TOTAL ALL EXPENSES $ _____

BOTTOM LINE $ _____

• Some expenses (like utilities) will change throughout the year, so use a monthly average.

Adapted from the American Banking Association Education Foundation

Chapter 10:
Friends and Fun: Having Adventures

What do I like to do in my free time?

What are my hobbies?

Who are my friends?

What do I like to do for fun?

Most people enjoy "hanging out" with others. With cell phones, Facebook, Twitter and other social media you don't even have to be in the same room to hang out!

Some youth with disabilities spend hours everyday watching TV, playing video games or surfing the internet. Too much "screen time" can make you feel lonely and disconnected from others. Make time for doing things with other people!

Everyone is different and you may want to explore some new interests. Be creative! Plan to have fun! This is an important part of your life that you should think about while you are still in school. The key is to think about what you enjoy doing, finding others who enjoy it also, and setting aside time to play! ***Resources for Roadblocks***, Chapter 10, will give you more ideas.

There are lots of things to do: Do YOU

- Like to read, cook, exercise, or play on or manage a sports team?

- Play a musical instrument, sing, write songs or poems or short stories, knit or embroider, paint, or rebuild old cars?

- Enjoy being around animals? They are fun to watch and play with. Some pets can even be trained to be service animals.

- Go to movies or concerts?

- Like to visit with friends, go shopping, or hang out at the mall or other places?

- Participate in a religious community?

- Hang out with friends listening to music, watching TV, or playing video games?

- Go fishing, or work with flowers or houseplants, in a vegetable garden or on a farm?

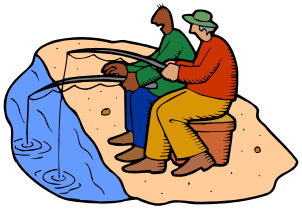
- Like to collect stamps or autographs, take pictures and make albums, or do graphic arts?

Relationships

A big part of the transition journey for youth with disabilities is learning to find people to like and love outside of the family. The topics of "relationships and sexuality" are often overlooked by families and caregivers as well as health care providers, teachers and others. At this point on your journey, it is time to focus on making close friends, accepting your body, and figuring out who you are and who you want to be.

Learning how to make friends is an important step on the road to becoming an adult. Good social skills are helpful in making friends, getting a job, and in finding a partner. Get involved in sports, school, work, or go to places where it is easy to meet people that like the same things you do and make you feel good about yourself.

Know that it is often up to the person with the disability to make the first move. Try to put the other person at ease and you will be more relaxed. After you get to know and trust someone, be honest about your disability. It is important to be clean and odor free. If you are trying to meet a partner, always look your best. Check the mirror before you leave home, and ask yourself: "Would you be attracted to that person in the mirror?"



Although a disability may affect how a person's body looks, feels, and moves, it usually does not affect the hormones that control sexual feelings. Most people with disabilities have the same need for intimacy, love and sex as anyone else—they may just have different ways to show these feelings. It is also normal to feel alone and confused at times. It helps to talk to friends, trusted adults, or someone that has the same disability that you do.

Find a balance in your life by getting involved in things outside of your home. Get sleep, good food, exercise, and view yourself like a future partner would. Think of ways to make yourself interesting! Concentrate on making friends and healthy relationships, and at the right time and with the right person, romance will follow.

Transition Activities:

- How do you stay connected with other people now? Are you involved with any groups, such as sports teams, school clubs, religious groups, or community volunteer groups? Do you have a computer and /or cell phone and stay connected through the latest social networking trends? What do you enjoy now? Will this change when you finish high school? What would you like to do in the future?

- In order to participate in your hobbies and other fun aspects of your life, do you need:
  - Help getting there?
  - Help finding places to do the things you like to do?
  - Help getting in touch with others who share your hobbies and interests?
  - Someone to help you once you are there?
  - Other kinds of help?

  Plan for this help before you leave high school! Be sure recreation and leisure are a part of your transition planning.

- Look for things to do in your community. You might find activities through:
  - Your city/county parks and recreation departments
  - Newspaper, radio stations, or television news program
  - Internet sites
  - Library
  - Your religious community
  - YMCAs/YWCAs
  - Community sports leagues
  - Free concerts at schools, parks, community or religious centers
  - Service projects, such as building a house with Habitat for Humanity, cleaning up the environment, working with a local animal shelter or food pantry
  - Involvement in advocacy work for persons with disabilities

Road Trip Summary

A good Transition Plan takes the
Dreams & Wishes
of the
Teen & Family
and creates a
Plan of Action with a Detailed Roadmap

Congratulations, you've reached the end of the book! We hope you have talked about hopes and dreams for the future. We hope this book helped you ask and answer lots of questions about possible destinations and ways to get there. We hope you got lots of information about health care, school, work and career, transportation, housing, money, and having fun. We hope you are better prepared for your journey to adulthood.

Remember to check your progress year by year. It is fine to take another look at possible destinations and remap your plans -- change is okay!

On the next pages is a summary form for you to use to keep track of things.

Good luck to you!

STUDENT Survey for Transition Planning
Plans for the Future

Today's Date:_____

Student Name:_____ Date of Birth:_____

School:_____ Grade:_____

These questions will help you think about what you might want to do when you finish high school. Each year, you can update this survey information to reflect changes in what you want to do as you get closer to leaving school. This information will also serve as a guide to you and your teachers in deciding which classes and educational experiences you should have to help you to achieve the kind of life you want to have after high school.

Health:

Are you able to tell others about your condition? Yes____No___

Do you have someone you can talk with about problems? Yes____No___

Are you independent in your health care (medications, treatments, therapies, equipment) and/or can you instruct or direct others to help you? Yes____No___

Do you know the effects of tobacco, alcohol, and drugs on your body and your condition?
Yes____No___

If you now see a pediatrician, do you have plans to find a doctor who cares for adults?
Yes____No___

Do you have plans for finding specialty care? Yes____ No___ Not needed_____

How will you pay for your health care?

School

Do you have an IEP/504 Transition Team to help you plan your future?

Do you know how to use a computer?

What kind of work would you like to be doing during the next school year?

Are you going out in the community for instruction during school day?
Yes_____No____ If yes, please describe:

Are you getting vocational training in real work settings? Yes_____No_____

Are you participating in any extra-curricular/after-school activities? Yes____ No___
If yes, please describe:

What kind of help do you need at school to be successful?

What do you need to know to help you live more independently in the community?

Legal Rights and Responsibilities at age 18

Do you know about your rights and responsibilities when you become a legal adult at age 18?
Yes____ No___

Work and Career

What year do you plan to leave high school?_____

Which of the following would you like to be doing after leaving high school? Check as many items as you wish.

- ☐ Job
  What kind of job?_____

  Do you have a resume? Yes___ No___

  What kind of help will you need to get and/or keep a job?

- ☐ Further job training (technical or trade school)

- ☐ Military

- ☐ Community College or University
  What kind of help will you need to go to college?

- ☐ Homemaker

- ☐ Volunteer Service

- ☐ Other (please explain)

Transportation

Do you have a plan to get your driver's license? (If unable to get a license, do you have a state ID card (available from the license bureau)?

Do you know how to use public transportation in your community?

How will you travel to your job or school?

How will you travel to community activities?

How will you pay for your travel in the community?

Living Arrangements

Where do you want to live after leaving high school?

	Immediately (right after high school)	**Long Term** (sometime in future)
With parents or relatives	__	__
With friends in an apartment/home	__	__
In your own apartment/home	__	__
In a college dorm or military barracks	__	__
In another type of "group" home	__	__

Other living options:

How will you pay for rent/house payment?

Do you know how to cook?

Do you know how to keep a home clean?

What type of help will you need to live in the places you have chosen?

Recreation, Leisure, and Social Activities

What do you like to do in your free time?

When alone:

With a group (e.g. family, church, school, neighborhood):

What kind of help will you need to participate in the things you enjoy doing in your free time?

Other Services

Please check all the services that you think you need now, and in the future, to be successful when you leave high school. Check as many boxes as necessary:

	Now	Future
Job training/support	___	___
Income support	___	___
Health care services	___	___
Transportation	___	___
Housing	___	___
Community skills training	___	___

Other services:

Now:

Future:

Other thoughts about planning for your future:

Student Signature:_____

Adapted from Student Survey for Transition Planning – Kentucky Transition Collaborative

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