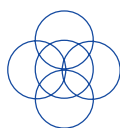


Healthy & Ready to Work:
A Series of Materials Supporting Youth with Special Health Care Needs

Transition to Adult Health Care: A Training Guide in Two Parts



Waisman Center
University of Wisconsin–Madison
University Center for Excellence in Developmental Disabilities



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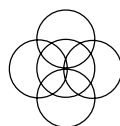
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Introduction

This training guide is intended to serve as a framework for anyone interested in helping young people with special health care needs and their parents prepare for the transition to adult health care. The Maternal and Child Health Bureau of the U.S. Department of Health and Human Services defines a child with special health care needs as:

“A child to young adult (birth to 21 years) with a long-term, chronic, physical, developmental, behavioral or emotional illness or condition. The illness or condition meets the following criteria:

- It is severe enough to restrict growth, development or ability to engage in usual activities;
- It has been or is likely to be present or persist for 12 months to lifelong;
- It is of sufficient complexity to require specialized health care, psychological or educational services of a type or amount beyond that required generally by children.”

This guide was developed using a collaborative approach, supported by both research and real-life experience. It focuses on some common questions and concerns, while allowing for individual differences in developing a plan for addressing them.

This training has been divided into two parts: Part One, aimed at parents of children with special needs, and Part Two, aimed at the young people themselves.

Some young people with special health care needs may require considerable help anticipating and understanding their adult health care needs, as well as how to get those needs met. Some may need very little additional support. Some of these young people may eventually become fully independent in managing their own health care. Others will continue to need assistance. The hope is that even those who will require considerable support will still be able to become more involved in this important area of their lives.

Because young people with special health care needs include many individuals along a continuum, it is important to acknowledge the uniqueness of the transition experience for each young person and each individual family. In all cases, however, we can safely say transition is a developmental process for parents and youth that cannot be accomplished in a single effort, but must happen over time.

Using this Guide

Every training situation is unique and each trainer brings both experience and personal style to the process. The material presented in both parts of this guide has been written in a script format that can be used almost verbatim. This may be especially helpful for new or less experienced trainers. Those with more experience may want to use the material presented as more of an outline. In either case, trainers should become familiar enough with the script material so they don't end up simply reading it to participants.

The guide includes activities for audience participation and forms that can be used as handouts and as overhead transparencies to guide the presentation of information and related discussions. Because of how it is written, parents or others who may be less experienced in workshop presentation may see this as an opportunity to develop new skills. This particular guide addresses some aspects of trainer preparation but focuses on the content and its presentation rather than the organizational tasks of workshop coordination.

Practical tips for presenters are incorporated into the script in special "boxes" labeled Trainer's Tip. The Tips help provide "stage directions" for moving through the presentation process. Presenters will want to pull in information shared by participants and tailor examples to meet their specific needs. Technical equipment has been kept simple. Presenters will need a flip chart with markers, an overhead projector with transparencies, and copies of the handouts for the participants. Be sure to prepare these in advance.

Pilot presentations using this material were conducted over the course of a year. Response has been favorable in terms of the content, format and the handouts. Pilot presenters included a parent and a young adult with special health care needs presenting both parts of the training; two parents presenting the parent workshop; and a solo trainer presenting to groups of parents and service providers.

With increasing frequency, presenters are wearing more than one hat and are using their experience as both parents and community service providers. The flexibility of the scripts should allow a variety of combinations to be successful.

In fact, the scripts and handouts can also be used in one-on-one training situations with either parents or youth with special health care needs. Parents may even wish to use Part Two as an outline for the informal day-to-day coaching they do with their son or daughter.

TRAINER'S TIP:

It will be essential for trainers to review the handouts in both Appendices A and B. Appendix A includes handouts for Part I and Appendix B contains the handouts for Part II.

Appendix C offers references and additional resources for enhancing knowledge of teaching/learning and a variety of special needs. These may also assist the trainer in further developing his or her own knowledge, or they may help in responding to additional needs identified by the workshop participants.

Overview

Part One

Part One presents a workshop for parents of young people with special health care needs.

Parents are not only involved in their child's transition but must also examine the changes in their own parental roles. This can be a stressful time, and preparing for transition to adult health care for their son or daughter, adolescent or young adult, may be something that seems overwhelming. Care must be taken to help parents use their previous experience, acquire new information, and develop a planned series of steps they can immediately use.

Parents need to be reassured that even if they think they are late in dealing with all that is involved, it is never too late to begin. There may be a variety of reasons for the delay. Encourage parents to regard this period of "delay" as an "incubation" period rather than "lost" time. If they can see it that way, they may be more inclined to move ahead now.

Principles of adult learning tell us that adults are motivated to learn the information and skills they need. They also want their learning to be active and practical. The script reflects these considerations. It is organized around seven activities.

The script for the parent workshop module can be used effectively with one or two trainers presenting to a parent audience. It can also be used in presenting to service providers or others in supportive roles. And, of course, it can be used to present to a combined group of parents and providers.

A typical timeframe for the workshop can range from two to four hours. The timeframe is influenced by time available, audience size and composition, as well as audience interaction. If adjustments for time need to be made, certain elements can be condensed. Each trainer will need to practice his or her own pacing, establish priorities for emphasis, and make the workshop "their own" while maintaining the essential themes and structure.

Part Two

Part Two of the training guide presents workshop material to be used with young people who have special health care needs.

It contains four modules, each in script format as in Part One. Each module has been developed into a two-hour workshop. The modules can be used together as a series or independent of one another. Pieces of each module can also be recombined to create yet another module based on the particular timeframe available or the make-up of the group attending the training. The series can be spaced out over several weeks or condensed into a one or two-day intensive session.

The basic content of the workshop and handouts is similar to the workshop for parents but is placed within a more youth-tested context. It can't be overstated that the needs and abilities of each group member in the training for teens and young adults will be unique. To some degree, this is true of every learning situation, including the workshop for parents. However, while the participants in the parent workshop group will also be unique individuals with differences in learning styles, their common denominator of being parents does serve as a powerful and practical unifying force.

In the workshop for teens and young adults, the common denominator is that they all have special health care needs. Because of the range of special needs possible, we thought it would have been disrespectful, as well as impossible, to develop a "one size fits all" training guide. The best we could hope to do is provide a presentation with materials that can be used or adapted to create training sessions that meet the needs of those in each participant group.

TRAINER'S TIP:

Be aware that Part Two, the teen and young adult training, will place more demands on facilitators because it requires more advance preparation, knowledge of the specific needs and abilities of participants, plus the ability to be creative and flexible in making the necessary accommodations for a successful learning experience.

Part One: A Workshop For Parents

Welcome

Welcome to this workshop. We look forward to spending some time today exploring how we can help our teens with special health care needs prepare for greater involvement in managing their own health care as they approach adulthood. For some, this involvement may actually contribute to full independence.

TRAINER'S TIP:

Trainers will want to give a brief welcome and introduction, including some of their experiences related to the transition of youth with special health care needs. If this is a small group presentation, it may be appropriate to invite workshop participants to briefly introduce themselves and state what they are hoping to learn from this experience or to voice their primary area of concern related to their child's transition to adult life.

If you have a large group and personal introductions are impractical, it still may be helpful to ask for a show of hands indicating the make-up of the group. (For example: parents, teachers, other professionals, or the ages of the young people with whom they are involved). Participants are more likely to feel comfortable and open to active participation if they feel they have common ground with others involved in this experience.

Topic Overview

Today's topic covers material that is important to know if you are the parent of a teen with special health care needs, but it can also be a little scary. Parents and teens may not even want to think about it. The topic is transition - a period of life that is a time of change in many areas for both you and your teen. There are many things to be thinking about and planning for. One of them is preparing for an important aspect of everyone's life - managing health care.

We can't tell you everything you as a parent need to know and exactly how to prepare your teen for this important aspect of transition to adult life - we are all unique individuals. This is also true of young people with special health care needs. There is no one approach that works for everyone. But there is some information that may be useful to you in

preparing your teen to take a role in managing, or helping to manage, his or her own health care needs and getting the appropriate assistance to ensure those health care needs are met.

During this workshop, we will present seven activities with questions for you to consider and tools you can use or adapt to create an individualized approach to your teen's health care. We'll focus on where to begin and how to access additional resources that may also help.

This is not something that can be completed in one step. It's a journey that takes place over a period of time. We will show you how you can use the materials in this workshop to begin the journey and to develop an action plan for achieving success. Let's start by thinking about time...and the future.

The Future Sneaks Up on You

"The fog comes on little cat feet." This is the first line of a poem by Carl Sandburg, one of the great American poets, and a Midwesterner who shows us that a few words can convey a lot of meaning.

Like a cat, fog moves quietly, slowly, almost without notice. Then, there it is, right in front of you! This can often be said of the future. We are all so consumed with the activities and demands of daily life that we sometimes lose sight of the future. But the future has a way of "suddenly" appearing and catching us off guard.

For parents of teenagers with special health care needs, being prepared for the future presents some unique challenges. These challenges are new ones for parents even though they may be "veterans" in so many other aspects of raising a child with special health care needs. When we look at how to meet these challenges, we may want to go back to Carl Sandburg's poem and look at it from another perspective. Parents may feel like they are in a fog. They may feel frozen. They may not know which direction to go. And so, parents may need to stop, re-orient themselves and then proceed slowly, to keep from becoming overwhelmed.

This journey can begin by taking advantage of the little opportunities in daily life to prepare young people with special health care needs for greater involvement - independence if possible - in taking care of their health needs. Parents are presented with many such opportunities every day. An example of such an opportunity - call it a “teachable moment” - would be when you make the next medical appointment for your teen. To make the moment teachable, use the appropriate “form” supplied later in this training - and in the process, show your teen how the form can help him or her handle making the appointment.

At first, using these “teachable moments” may seem like more work than reward, but the teen who becomes more involved will gradually gain more competence and confidence.

Since this workshop will give you plenty of material for teaching the appropriate degree of independence to your teen, you will want to look carefully at how much involvement or independence your teen may be able to manage at one time. This varies - depending on an individual’s abilities and needs - from moving toward almost complete independence to requiring care or assistance in virtually every area of daily living. But even for individuals requiring extensive care, there may be choices they can make and ways for them to participate in their own care.

Anyone who has observed young people moving toward adulthood knows that even teens without special health care needs don’t get struck by a bolt of lightning, instantly making them competent, fully independent adults. Ultimately, we all learn by observing how things are done and then by doing them ourselves. And most parents don’t disappear from their children’s lives at the stroke of midnight on the child’s 18th birthday - or ever!

Parents do increasingly find themselves relegated to the sidelines. But that’s OK, because everyone knows who’s on the sidelines - the coach! We all know from our own experience with growing up that adulthood is a whole new ballgame. So, as parents, don’t overlook how your knowledge and experience will be extremely valuable in your new role - as the coach.

Play Ball!

Well, since we have taken the lighthearted view that life is a ballgame and you, the parent, are the coach, let’s make use of the metaphor to organize our exploration of the elements necessary for helping your teen transition to adult health care.

✓ Activity One: What Makes A Great Coach Great?

You may be wondering what you know about coaching. Don’t worry if you feel unprepared. Even the greatest coaches didn’t start out great...they grew into their roles one step at a time, and so will you.

TRAINER’S TIP

In the Great Coach activity you will be defining what the coaching role is. Encourage participants to offer ideas. Write down all of them on the flip chart, but try to shape the wording on some of them to reflect at least some of the following (or add them in yourself):

- knowing the rules
- understanding the game
- knowing the strengths and weaknesses of the player
- providing honest but positive feedback
- realizing that “you win some and you lose some”
- creating a game plan - which stays flexible
- practicing, practicing, practicing

Leave time for questions and answers. Summarize once your list is complete, or time requires you to complete it.

There are some things that help every coach whether on the practice field or during the game. Let’s brainstorm a list of what it takes to be an effective coach. We’ll keep track of these ideas on a large flip chart sheet.

Rules of the Game

Every coach also has a playbook, a collection of strategic documents that guide success. In our case, the handouts from this workshop will make up

your playbook. They will give you materials strategically framed to help you and your teen - the player - cope with making the transition to adult health care. The first handout is **what every coach and player must know** - the rules of the game, or in this case, the rules that come with reaching age 18.

TRAINER'S TIP:

Distribute copies of handout A1, Appendix A called **Rules of 18**. You may also want to have an overhead transparency of the handout to show as you review the various rules. While you review them, invite participants to offer comments, observations or questions on each rule.

Turning 18 is a "magic moment." Just like that, Presto! Your teen is legally an adult. This is the first page in your playbook because you must understand what happens when your child reaches that critical 18th birthday. Knowing the ground rules - the Rules of 18 - is the first step toward designing the coach's game plan for players. Your individual "game plan" is really based on how you put together the handouts and information in this training. Now lets go on to step two.

✓ **Activity Two: Knowledge of the Game**

In order to create an effective game plan, you need to know the challenges you are preparing your player to meet. Some of those have been identified in the rules we have just discussed. Now let's take another perspective on those challenges. Your second step is to determine what parents should expect their teens to know in order to be ready for adult health care. Or what "knowledge of the game" should the Coach expect from players...before the game even begins.

TRAINER'S TIP:

Distribute copies of handout A2, Appendix A, called **Transition to Adult Life: Knowledge of the Game**. You may also want to have an overhead transparency of the handout to show as you review the six points of knowledge explored in the handout. While you review them, invite participants to offer comments, observations, or questions on each rule.

Let's look at the handout titled Transition to **Adult Life: Knowledge of the Game**. This handout explores the basics of what we want young people with special health care needs to know and be able to do, to the fullest extent possible, in order to be prepared to handle their health care needs.

We'll go through the handout together, and if you have anything you'd like to say or ask, please feel free.

Just those six basics are a lot. But they're also part of the adult game of life. Your teen or young adult may not show an interest in any of this, but just like you helped prepare him or her for other big steps in life (remember getting ready for kindergarten?) you can help prepare for this transition. So, the question is..."How can parents coach their teens to get them ready to take the field, ready to play?"

✓ **Activity Three: Pre-Game Coaching - A Parent's Health Care Checklist**

As a parent, you should know if your player needs coaching in any particular skill. Our next handout, **A Parent's Health Care Checklist**, will help you with your game plan. It will give you an idea of what your teen needs to know - and what you know about your teen's readiness to handle adult health care needs. It will help you know where pre-transition coaching is needed.

TRAINER'S TIP:

Make sure each person has a copy of **A Parent's Health Care Checklist**, handout A4, Appendix A. Again, you may want to have an overhead transparency of the handout to help you explain the directions you will be giving.

Take a few moments to look over the handout. If you and/or your teen has mastered the area covered in each question, check the Yes column. Check the Not Yet column, if you're still working on it. Don't worry about the third column right now. We'll come back to this near the very end of this workshop.

✓ Activity Four: Profile Your Player

Parents may feel they are getting to know their child in a whole new way. This is indeed what should be happening. As coaches, parents need to reflect on what they already know about their player and how that knowledge applies to this new phase of transition to adulthood.

TRAINER'S TIP:

Make sure each person has a partner and a copy of the handout called **Player Profile Interview Format**, A5 in Appendix A, and a pen or pencil. Have extras on hand. Review the elements of the form so they can begin formulating ideas and ask for any necessary clarification. You will break up into pairs for an interview. Given your sense of time, it would be best if you could switch the interviewer/interviewee roles so that everyone gets a chance to be both. This could be time-consuming, so plan with time in mind.

Parents also need to be open to making new discoveries about their player and seeing new possibilities. How would you describe your player?

Because it can sometimes be difficult to think openly and write notes at the same time, let's break up into pairs. Using the Player Profile Interview Format handout, we want you to interview your partner about his or her player.

- The interviewer should write some brief notes in the spaces provided. You're basically asking for a capsule description of the player.
- The person being interviewed should describe the player's special health care needs, talents, likes and dislikes, as well as how that player learns best. What are your goals for this player? How independent or involved do you hope he or she can become? You know your player well, but we want you to put that knowledge into words.
- To respect everyone's privacy, share only what you feel comfortable disclosing in this setting.

We'll take about 10 minutes to do the exercise. You should switch roles so both partners get to be interviewer and interviewee. Don't worry about the time. We'll tell you when it's half time and also give you two-minute warnings.

TRAINER'S TIP:

Walk around so you are available to anyone with questions. Be accessible but not intrusive. Be sure to keep track of the time and give the warnings as promised. When time is up, you will ask the participants to share some of their observations about their teens, about themselves or about the exercise. Write some of these in phrases on a large flip chart.

Now let's share our observations so we can see some of the common ground and some of the differences we bring to this discussion.

TRAINER'S TIP:

When talk begins to diminish, go on to ask the questions below. If people want to share their responses, let them, or simply pose the questions as rhetorical, for consideration. Being prepared with some of the background information and strategies from Appendix C may be extremely valuable in the discussion about how to accommodate learning/communication needs.

Here are some questions to help you continue to consider what you know and understand about your teen. Comment if you like, or jot the questions down for later reflection.

- If we asked your teens these same questions, how would they answer?
- What are your teen's goals? Do they have any?
- What are your teen's ideas and expectations about adult life?

TRAINER'S TIP:

The rest of the material in Activity Four is information you will convey directly to participants. Look it over and get a good grasp on the script for a confident delivery.

Good Coaches Follow Up On What They Learn

The Player Profile exercise may have given you ideas for discussions you might want to have with your teen. It may have helped you identify topics you can talk about in frequent, short discussions at home at the dinner table, or during the commercials of a television program you share. Perhaps you can find an opportunity after watching a movie together, or while driving in the car.

In any event, help your teen by talking about what life as an adult has been like for you. Share the opportunities as well as the challenges. Describe some of the skills and perspectives you've developed along the way. And be sure to tell your teen what you think his or her strengths and talents are, and how these will help in his or her own transition to adulthood.

Consider Your Teen's Learning Style

What do you know about how your teen learns best? People have different learning styles; some are verbal, some visual; some learn by hearing, or by touch. You may need to present some information verbally and some visually, in written form, in photographs, videotapes, diagrams, or symbols. You may need to use audiotapes or other ways of delivering information orally. You may need to help your teen learn non-verbal cues. You may need to repeat some things over and over.

With all of the technology available, the possibilities for teaching tools are almost unlimited. Seek help in learning new ways to approach your teen. There are a number of brief books on "Learning Styles." Your efforts will demonstrate to your teen that we can all benefit from being lifelong learners.

Listen to how your teen describes his or her special health care needs. That's your baseline, or starting point from which you can measure improvement. Your teen may need help in knowing what to say in different situations, how much information to share, and how to make the information appropriate to the situation.

Giving your teen opportunities to practice using his or her own words or way of communicating in different situations may be helpful. For youth who are non-verbal, this may include using an augmentative communication device, written responses, pre-printed pictures or symbols. You can role-play different options by posing situations you know they will encounter, such as these examples:

- "What if someone asks you about yourself at the mall or at church? What might you tell them?"
- "What if you are meeting a new doctor for the first time? What would you want to tell that person?"

- "What if you are seeing your doctor because you're having a problem or don't feel well? How will you communicate this?"

You can help your teen understand privacy and boundary issues by talking about how much you share with your doctor and others. You can also demonstrate this by showing discretion in your own conversation about some aspects of your teen's needs.

You can help your teen get used to giving information, answering questions at a doctor's appointment, and perhaps even spending some of the time at their next appointment without you immediately present.

Remember that although your teen has some special needs, in many ways he or she is a "typical" teen, so don't forget to cover the same issues and concerns you would with any teen - and ask the health care providers working with your teen to do the same. If medical personnel only address you as the parent, you may want to encourage them to communicate directly with your teen.

Establish a "Medical Home"

The Medical Home Concept, as described by the American Academy of Pediatrics, embodies the way care is provided rather than referring to a place. Within a Medical Home framework, the pediatric health care professionals and the parents work as partners to identify and access medical as well as non-medical services needed to reach the youth's greatest potential.

Having health care providers who are familiar with your teen and with whom your teen feels relaxed can be a strong advantage in establishing a Medical Home. Because trust is a key element in this working relationship, parents should be able to approach these partners as resources in discussing sensitive subjects such as sexuality, alcohol or drugs, safety and vulnerability, and other lifestyle challenges.

Your health care partners should also be helpful in making recommendations about adult health care providers and when a change to an adult provider might be most appropriate. These same partnering principles can be used to create a similar framework in establishing adult care.

✓ Activity Five: Providing Your Player with the Right Gear

Use what you've learned about your teen to choose "informational gear" that will help him or her succeed in the game, which is success in dealing with adult health care. This section of the workshop will be devoted to going over some carefully constructed forms that are useful guides to dealing with common challenges.

Consider these forms to be the bats and balls, the pads and guards your teen needs to perform like a pro.

TRAINER'S TIP:

This section of the workshop is devoted to the following group of handouts from Appendix A:

The Schedule - **Daily Planner**, handout A3

The Coach's Key Signals - **Emergency Information Card**, handout A7

The Player's Play Book:

Making an Appointment, handout A6

Ordering Prescriptions and Refills, handout A8

Transportation for Medical Appointments, handout A9

Visiting a New Doctor, handout A10

Visiting My Regular Doctor, handout A11

The Team Roster, handout A12

When I am Sick, handout A13

The Business End - **Health Care Financing Fact Sheet**, handout A14

Be sure to review these handouts and work out a time scheme for presenting them in the time you have remaining.

The Schedule: A Monthly Calendar and a Daily Planner

Each person needs to find a method of planning that is most effective. Some people use a big monthly calendar strategically placed where they will see it at key points in the day. Some carry a smaller month or day planner with them. Some people are list makers. There are many people who have multiple planning tools. They may have a personal

calendar, a work calendar, and a family calendar where they keep track of their own and others' day-to-day commitments and activities.

Almost everyone benefits from having some sort of calendar to help them keep track of appointments and opportunities. Players know their schedule for a whole season. A monthly calendar can be used to keep track of appointments, be a reminder for ordering prescription refills or supplies, scheduling maintenance checks of equipment, or planning for home health care assistance. It provides that big picture overview.

Providing structure to each day helps all of us accomplish more of what we want to do with our time. Schedules can be used to plan the day ahead, help us keep track of what has been accomplished, what remains to be done, and serve as a tool to review at the end of the day and feel good about having a purposeful and productive day. Let's take a look at a sample Daily Planner.

TRAINER'S TIP:

Distribute copies of the **Daily Planner** handout. (A3, Appendix A). In your discussion, point out that this handout is a tool to get them started. It can be copied and used as a daily planner or as a bridge to finding out what kind of planning tool might work best. You may want to have an overhead transparency prepared showing one or more examples of how this planner can be used as a tool for reminding the player about activities that are difficult for them to remember or are a high priority. A sample filled out form is on the following page.

For players who can read, use words or short phrases to fill in the planner. For someone who is not able to read, use words, pictures or symbols instead. In some instances, photographs might be used. Adaptations can be made through a variety of low or high tech means.

In addition to being two kinds of reminder, a calendar and a daily planner help to avoid over-scheduling as well as under-scheduling, and they help to identify opportunities for filling time gaps in productive ways.

Daily Planner (Sample)

TIME	ACTIVITY /WHERE /WHO	SPECIAL REMINDERS
7 am	Get up and shower, wash hair and brush teeth	
Noon	Take meds with lunch at work with this med	Don't have orange juice
Before Bedtime	Lay out work clothes for the next day	Remember to set alarm clock

The Coach's Key Signals - Emergency Information Card

Every player needs a place to keep track of important information, such as the coach's signals. In our case, your teen needs a way to maintain basic health information and keep it available as a handy reference and for emergencies.

TRAINER'S TIP:

Distribute copies of the **Emergency Information Card**, handout A7, Appendix A.

There are many different types of emergency information tools. The handout you have can be posted on a refrigerator or somewhere else in plain view and be used by first responders in an emergency, or can be a quick "take along" in case of an emergency room visit. You can make extra copies and have them in several different places.

Your Player's Play Book

In addition to the **Emergency Information Card**, there are other informational forms that can help your player be prepared to handle certain common health care situations, such as seeking medical attention.

TRAINER'S TIP:

Review the handouts for each of the situations listed below. Facilitate discussion of how they may be adapted so they are more suitable or easier to use based on the individual's unique needs and abilities. These handouts are in Appendix A.

Take a moment to look at the six handouts that deal with these common situations:

- **Making an Appointment-A6**
- **Ordering Prescriptions and Refills-A8**
- **Transportation for Medical Appointments-A9**
- **Visiting a New Doctor-A10**
- **Visiting My Regular Doctor-A11**
- **When I am Sick-A13**

The Business End - Insurance/Payment Information

How medical care is paid for is obviously very important. This is also an area of constant change and one in which "reading the fine print" is especially important. The fact sheet on **Health Care Financing** provides some information about payment and financial issues.

TRAINER'S TIP:

Review handout A14 entitled **Health Care Financing Fact Sheet** in Appendix A. Be sure to point out that there are advocacy organizations available to assist in understanding and accessing insurance and related information - and that it's always a good idea to seek help because the information can change.

✓ Activity Six: Team Roster

Don't forget, you are not alone. Keep track of who else can help you. There may be teachers, friends, relatives, neighbors or others who are able to help out. Also, keep track of local, state and national organizations, and the support resources you can use.

Don't just think about these important resources as abstract possibilities. Write them down and actively engage them. If your teen is in school, these resources, along with other elements of transition, need to be considered in his or her IEP (Individual Education Plan). For health related concerns, the school nurse can be a valuable asset in developing a health plan that helps the student learn about his or her care needs and self care skills. Patient education is a key component of the nursing role.

Right now, we're going to examine two more handouts.

TRAINER'S TIP:

Two sample **Team Rosters** are on the pages following this one. Review them and refer your participants to the blank **Team Roster**, handouts A12 in Appendix A. Encourage participants to think who they might include. Remind them that team members may also change roles over time. In fact, that can be a goal of the transition process. A parent may begin as coach but another friend or relative or even a care provider may assume that role. Eventually a player may even advance to the point where he or she has a strong staff of assistant coaches providing support. Encourage some discussion of these possibilities by the participants.

Also have the participants fill out handout A15, Appendix A, called **Your Coaching Resume** to remind themselves of the many skills they already possess.

Team Roster (Sample)

MANAGER	Nora's Dad _____
COACH	Nora's Mom _____
ASSISTANT COACHES	Nora's Brother _____
	Nora's County Social Worker _____
	Nora's County Nurse _____
	Nora's Primary Doctor _____
	Nora's Aide at School _____
POSITION COACHES	Nora's Respite Provider _____
	Nora's Specialists for Medical Care _____

TEAMMATES	Friends at School _____

	Friends at Special Olympics _____

	Friends at Work _____
	Friends at Synagogue _____
CHEERLEADERS	Neighbors Mike and Paula _____
	Grandma, Aunts, Uncles and Cousins _____

Other community support people like hairstylist, grocery store clerks, etc _____	

Team Roster (Sample)

MANAGER	Sam's County Case Manager _____
COACH	Sam's Mom _____
ASSISTANT COACHES	Sam's Sister _____
	Sam's Neighbor _____
	Sam's Cousin _____
	Sam's Primary Doctor _____
	Sam's Job Coach _____
POSITION COACHES	Sam's Special Olympics Coach _____

TEAMMATES	Sam's Video Game Buddies _____

	Sam's Classmates _____
	Members of Sam's Church Choir _____
CHEERLEADERS	Sam's Friends _____

	Sam's church Congregation _____

✓ Activity Seven: Health Care Checklist Revisited

Now, let's return to the **Parent's Health Care Checklist**. You filled out two columns earlier. Now we'll work on the third column. Select two or three items on the list and write down some first steps you can take to begin working with your teen in these areas.

This is where you begin. Start small. Start slow. Start now!

Remember, success in any game takes practice, practice and more practice. No matter how good you are, you can't win every game. There may be situations that just don't go as well as hoped. But now you have some tools to review the play and try again the next time.

These tools - which are primarily the handouts - are your playbook. Continue to add new information and tools as time goes on. Share these with the others on your team. Everyone needs to be working from the same playbook to work together.

Finally

We hope we have given you a practical way to break a very big job into smaller, more manageable steps. We also hope we have given you some ideas for having a little fun with this as well.

Harold and Maude is a novel by Colin Higgins. It was made into a movie by the same name. It's about an 80 year-old woman named Maude and the lessons she teaches a young man named Harold about the "game of life."

At one point, she gives Harold some advice about getting into the game. She says... **"Reach out! Take a chance! Get hurt, maybe. But play as well as you can... Otherwise, ... you'll have nothing to talk about in the locker room."** (Higgins 1971, 90)

Don't wait for everything to be just right. Don't wait to be the perfect coach. Just be the best coach you can and continue to learn along the way. Start small. Start slow. Start now!

Part Two: A Workshop Series for Teens and Young Adults

Introduction for Trainers

Part Two of the training guide presents workshop material to be used with young people who have special health care needs. It contains four modules, and each module has been developed into a two-hour workshop. The modules can be used together as a series or independent of one another. Pieces of each module also can be recombined to create yet another module based on the particular timeframe available or the make-up of the group attending the training. The series can be spaced out over several weeks or condensed into a one- or two-day intensive session.

The basic content of this workshop and its handouts is similar to what is covered in the workshop for parents, but it is set in a more youth-tested context. We can't stress enough that the needs and abilities of each group member in the training for teens and young adults will be unique. Because of the myriad of special needs possible, we thought it would be disrespectful, as well as impossible, to develop a "one size fits all" training guide. The best we could hope to do is offer a flexible presentation of materials - materials that trainers can use or adapt to create training sessions that meet the needs of those in each participant group.

Using this Guide

The material presented in this part of the guide has been written in a script format that can be used almost verbatim. This may be especially helpful for new or less experienced trainers. Those with more experience may want to use the material presented as more of an outline. In either case, be familiar enough with the script material so that you do not end up simply reading it to participants.

The guide includes activities for group participation and handouts that can be turned into overhead transparencies. Use the handouts and overheads to guide the presentation of information and the related discussions. Because of this approach, those who are less experienced in workshop presentation may see this as an opportunity to develop new skills. This particular Guide offers organizational and practical tips for trainers, but focuses on clear and useful presentation of the content rather than on how to do the organizational tasks of workshop coordination.

Practical tips for presenters are incorporated into the script in special "boxes" labeled Trainer's Tip. The Tips help provide "stage directions" for moving through the presentation process. Presenters will want to pull in information shared by participants and tailor examples to meet their specific needs. Technical equipment has been kept simple. Presenters will want to use a flip chart with markers, an overhead projector with transparencies, and copies of the handouts for the participants. Be sure to prepare these in advance.

TRAINER'S TIP:

Be aware that this training for teens and young adults requires considerable advance preparation, knowledge of the specific needs and abilities of participants, plus the ability to be creative and flexible in making the necessary accommodations your participants need for a successful learning experience. It's a good idea to review the participant registration list prior to the training, and prepare the appropriate accommodations.

The variety of modifications needed may include changes in the amount of information presented in any given module, individualized support and assistance, individualized methods of communication, or physical and space accommodations.

Some of the participants may be able to read, speak and write. Others may not. Some may use augmentative communication devices. If you get to know the group members individually and how to include in your discussions examples relevant to their circumstances. But don't overlook the assistance that group members can lend one another. And remember to follow the same advice you will give them throughout this series...ask for help.

It may make sense and be a lot more fun to have co-trainer(s) who will be able to lend additional creative talents and energy.

Review the handouts in Appendix B. Make copies and overhead transparencies as appropriate. You'll need an overhead projector, large flip charts with markers, paper, and pens. As you study and prepare the modules, plan your needs. It would be good, for example, to know exactly how many handout copies you need for each module. Refreshments may also be a consideration.

Appendix C offers references and additional resources for further knowledge of a variety of special needs as well as for information on teaching and learning. Presenters should make copies for participants. The resources can help in responding to additional needs identified by the workshop participants. Presenters can also use the resources to supplement their own knowledge.

Module One:

Self-Awareness

Welcome and Introductions

Welcome to this workshop for teens and young adults. Everyone attending this workshop is getting ready for adult life. Becoming an adult involves a lot of changes. But like many of the other changes you've already been through, you have lots of experience to draw from and people to help you.

It's an exciting time!

TRAINER'S TIP:

Introduce yourselves and begin to make a connection with the workshop participants. Use your own techniques for developing relationships and promoting interaction as a tool for learning. This will put your participants at ease and prepare them for a style of collaborative problem solving

Topic Overview for Participants

When you become an adult, you'll have more freedoms. You'll also have the responsibilities that go along with those freedoms. Part of what we want to do in this workshop is take a look at how you can be better prepared for both the freedoms and the responsibilities of adult life.

According to the law, all you have to do to be an adult is become 18 years old. That sure sounds simple, doesn't it? But turning 18 doesn't mean you'll instantly know everything you need to know about being an adult.

As an adult, you may be responsible for making a lot of decisions. Of course, this doesn't mean you have to be alone in making these decisions. In fact, most people have others in their lives as support people to help them think through ideas and give feedback on important choices.

Many of you may already have parents, teachers, doctors and others who help you make decisions. You'll want to think about how to keep some or all of those people involved in supporting you in the years ahead. There may also be some additional individuals you will want to involve.

In order to make decisions that will work well for you, it's important to know more about yourself, and to think about what you want out of life. You may

want to start becoming more involved in taking care of yourself and your needs. In this workshop, we'll look at some of the things you need to know about taking care of your own health. We want you to be healthy and ready for life.

Group Welcome

Right now, let's take a few minutes and get to know each other a little better. You may be wondering who we are, and we would like to know a little more about you. So let's begin with introductions. Let's all give our name and age and tell a little something about ourselves. Please understand that throughout this workshop, we only want you to share what you feel okay talking about. You don't have to share something you want to keep private.

If you need some help with writing things down or need help with communicating what you want to share, just let us know.

As presenters, we will go first. We're going to record this on the flip charts so then we can talk about what we learn about each other.

[TRAINER: Adjust the following comments to fit your group]

TRAINER'S TIP:

Write the information shared on large sheets of paper to keep track of it for further discussion. You may want to read the information back to the group after it has all been collected.

As you can see, many of us have things in common. In some ways we are all a lot alike. In other ways, each of us is different. Some of us are the same age, or have the same color hair or eyes. Some of us may have similar interests. But even if we have interests that are similar, we are bound to have others that are different. You might even say that the one thing we all have in common is that each of us is different. This list shows us how true that statement is. Now that we've gotten to know each other better, let's talk about each of us getting to know ourselves.

Self-Awareness

Really getting to know ourselves better is part of getting ready for adult life. Self-awareness is one of the building blocks of a healthy life. Self-Awareness includes knowing:

- Our strengths
- What we need
- Our challenges
- What's important to us
- What we want
- Our responsibilities

Our strengths include our natural abilities, the way we affect the world around us just by existing, talents we have developed, and personality traits that are helpful to us. Challenges may include visible and invisible disabilities, chronic illness, undeveloped or underdeveloped skills, and personality traits that are not helpful to us.

What we want helps us decide on our goals for the future

What's important to us can help us understand what we want and how the things we want can affect our goals. Sometimes what we want is different from what we need or what will be good for us. I may, for example, want to eat a hot fudge sundae every night, but that would affect my health...and the size of my stomach.

It's also good to understand what we really want and need when we decide how to use our time. We could watch TV all day - which may be something we think we want. But it might be better to get out part of the day for fun or for volunteer work. It be may be better to watch TV only when there isn't something better to do or a favorite program is on.

Once we know that what we need and want is important to us, and not harmful, we can start finding a way to get it. If friendships are important, then we need to learn about and do the things that promote friendships. If good health is important, then we need to find out how to maintain good health.

If we think about what we want in our lives and from our lives and then work out plans to make those things actually happen, we can turn wishful thinking into reality.

But first we have to think about our responsibilities to ourselves and to others, and see if they are affected by the things we want and need before we finish our plans to pursue those things. Sound complicated? It is. That's why it's important to think about these things instead of just floating along and going whichever way life seems to take us.

✓ Exercise One: Famous Names

When our challenges include a disability or chronic illness, we may feel discouraged by that. We may also feel alone. But there are more people than we realize who have faced similar challenges. Some of the names may surprise you, and some you may already know about. Let's write their names on our flip chart, and maybe you can even add a few more to our list.

TRAINER'S TIP:

Make a list of famous people with special needs with input from the group. Write the names on a large flip chart page. Having some examples to share with the group and get them going on this exercise may be helpful. It may also be a good idea to select individuals who reflect the make-up of the group and who show the wide variety of special needs as well as the diversity of those included.

Some celebrities have been very open about challenges they faced. For example, actor Tom Cruise has talked publicly about his struggle with reading and how it affected him as a young person and even as a successful movie star. (*People Magazine, July 21, 2003*)

Others, like Mattie Stepanek, who had a form of muscular dystrophy and wrote several best-selling books of poetry (*Hope Through Heart-Songs, Hyperion Press, 2002*), became well-known because of their achievements as people with disabilities.

Still others are historical or political figures like President Franklin D. Roosevelt, who had polio, or Senator Robert Dole, who lost the use of one arm in World War II. Other famous people with special needs include sports figures, artists, scientists, etc. There are several web sites that provide more information about well-known people with special needs, such as www.learningdisabilityforum.com. It might be a good idea to prepare an extensive list in advance so you will be more likely to reflect the group.

In reviewing our list, we can see that a lot of people have had to accommodate some type of disability or chronic illness. It's important to realize that all of these people and all of you are more than just your disability or chronic illness. Learning how to be as healthy as you can so that you can be ready for the opportunities ahead for you in your life involves paying attention to every aspect of yourself and finding ways to make all of those aspects add up to a better you.

✓ **Exercise Two: The Ultimate Reality Show!**

How many of you watch any of the reality shows on television? Let's make a list of which ones and what you like best about them. We'll write your answers on this flip chart. Let's brainstorm and see how many ideas we can list.

TRAINER'S TIP:

In this second exercise, the participants will name favorite reality shows on television. Write the titles on the flip chart and review them after the group completes the brainstorming phase.

How many of these things are like real life and how many are not?

You might say that being an adult is the ultimate reality show. But you aren't going to have a camera crew following you around and you aren't trying to win a million dollars. You are trying to make the best life you can. You want to have some fun, but you also want to make choices that will help you get what you want out of life.

✓ **Exercise Three: About Me**

To make good choices for getting what you really want out of life, it is important to know yourself well. Let's use the **About Me** handout to help us get to know ourselves a little better.

TRAINER'S TIP:

For this exercise, distribute copies of the About Me handout, number B1 from Appendix B, and use the flip chart to list responses after participants have taken some time to fill out the **About Me** handout.

Take a little time to think about a few of your strengths, some of your own challenges, some of what you want in life and what's important to you. Then we'll compare notes. We'll take about 15 minutes to do this, so be brief. If you want, you can work with a partner. If you can, write some of these things on the handout. If you need help, just let us know.

Remember, we only want you to share what you feel okay talking about. You don't have to share something you want to keep private. Now, let's make another list on the flip chart of what you came up with and are willing to share.

Adult Responsibilities

We mentioned earlier that gaining self-awareness includes knowing our responsibilities to ourselves and to others. We need to understand ourselves to know what it means to be responsible to ourselves. Knowing our responsibilities to others begins with being aware of what it means to be an adult. Let's look at the handout called **Rules of 18** and talk about the rights and the responsibilities that come with being 18 years old.

✓ **Exercise Four: What Does it Mean to be Healthy?**

To this point, we've spent some time getting to know one another better, learning about ourselves and what we want, and exploring our responsibilities as adults. Now let's look at how all of this applies to our health, because maintaining good health gives us the foundation we need to pursue other life goals.

What is health? What does it mean to be healthy? Does anyone have any ideas? Let's brainstorm another list.

TRAINER'S TIP:

Some examples of what it means to be healthy might include feeling good, having energy, eating good food, exercising, maintaining a healthy weight, good dental care, being clean and well dressed, having friends and having meaningful things to do.

✓ **Exercise Five: Healthy Lifestyle Habits**

As you can see, there are many pieces that go into making a person as healthy as possible. One way of putting all these pieces together is to cultivate what we call **Healthy Lifestyle Habits**. Let's take a look at a handout called Healthy Lifestyle Habits. We'll explore physical wellness from diet and exercise, emotional wellness from seeking balance, social wellness from healthy relationships and the overall need for self-awareness and self protection. Let's talk a little about each of these kinds of wellness and brainstorm what each of them makes you think of so we can list them on our flip chart.

TRAINER'S TIP:

Distribute copies of the **Healthy Lifestyle Habits** handout B5 in Appendix B. Be prepared to discuss the four areas listed on that handout and to once again list participants' responses on the flip chart. For your own information, the remaining three modules cover the areas of physical, emotional and social wellness. Depending on your time constraints and plans for other modules, you may want to see if any material from those modules would be helpful here. When the exercise is complete, distribute copies of the two-page **Health Care Checklist**, handout B4 in Appendix B.

Since you will be referring to both of these handouts in the other three modules, you should advise participants to bring these handouts with them to the other module workshops. And be sure to keep extra copies on hand.

Make a List and Check it Twice

How ready do you feel to tackle some of the things we've talked about today? To help you know where to start, we have a **Healthcare Checklist**. Let's go through the list. First, check off the things you think you already know something about in the "Yes" column. Next, check off the things you still want to learn more about by putting a checkmark in the "Not Yet" column. If there are a lot of things you still want more practice with, don't worry. We will work on them one by one and together we will help each other be ready to tackle the challenges of getting ready for adult life!

Module Two:

Physical Health and Wellness

TRAINER'S TIP:

Once again you'll want to assemble the handouts you'll need from Appendix B for this workshop and familiarize yourself with them as the basis of this module. There are eight handouts:

1. **When I am Sick** - B3
2. **Visiting My Regular Doctor** - B6
3. **Visiting a New Doctor** - B7
4. **Making an Appointment** - B8
5. **Transportation for Medical Appointments** - B9
6. **Ordering Prescriptions and Refills** - B10
7. **Emergency Information Card** - B11

Make extra copies to use as in-class samples. Be sure there are enough so that participants can take home clean copies. Don't distribute these handouts all at once. Do it in the sequence followed by the text. Pass each out in the section where it's discussed. You may find it helpful to make overhead transparencies of the handouts. Based on your knowledge of the participants, if there seems to be too many to cover in one session, select fewer and just let the group members take the remainder of the handouts home to complete outside of the workshop, or break the workshop into two sessions.

You may also want to review some of the material from the previous module by going over the **Healthy Lifestyle Habits** handout used in Module One (B5, Appendix B). Be prepared to have additional copies of this handout available for anyone who does not have it from the previous session.

Review and Introductions

Let's go around and introduce ourselves again and welcome anyone new to the group. Let's also take a look at the **Healthy Lifestyles** handout we used last time to get us thinking about the different aspects of living a healthy life as we prepare for our adult lives. Does everyone have a copy of that handout?

Now we want to turn our attention to the physical aspects of **Health and Wellness**. On the **Healthy Lifestyle Habits** handout, you'll see that Physical Health includes diet and exercise, your overall health condition, managing your physical needs and taking care of your personal appearance day-to-day. It also involves getting regular health and dental checkups.

Let's review how physical health fits into the overall healthy lifestyles model we are using. Having a diet that includes wholesome foods instead of a lot of fast food is important to maintaining a healthy weight and providing us with the energy to do the things we want to do in life.

In recent years, we've also learned how important it is to drink enough fluids, and to be sure we are getting enough water so we don't become dehydrated. Drinking too much soda and sugary, flavored drinks can add a lot of empty calories and make it hard to keep a healthy weight. We also know that too much fat in our diet can be unhealthy and lead to heart disease and other problems.

Exercise can help us in many ways, and it's important to get 30 to 60 minutes of exercise 3 to 5 days every week. There are many ways to exercise, so there is usually something for everyone. It may take trying out different activities until you find one that is right for you.

Keeping up our general appearance is also a part of physical health. Making sure we brush our teeth, bathe or shower, keep our nails and hair clean, and wear clean clothes contributes to our personal appearance. It can be hard to remember some of these things, especially if we have a limited amount of time in the morning or at night due to work or school schedules. It may help to have a checklist or some other way of reminding ourselves about these important tasks. Sometimes a roommate or support person may be able to help us remember.

When I am Sick

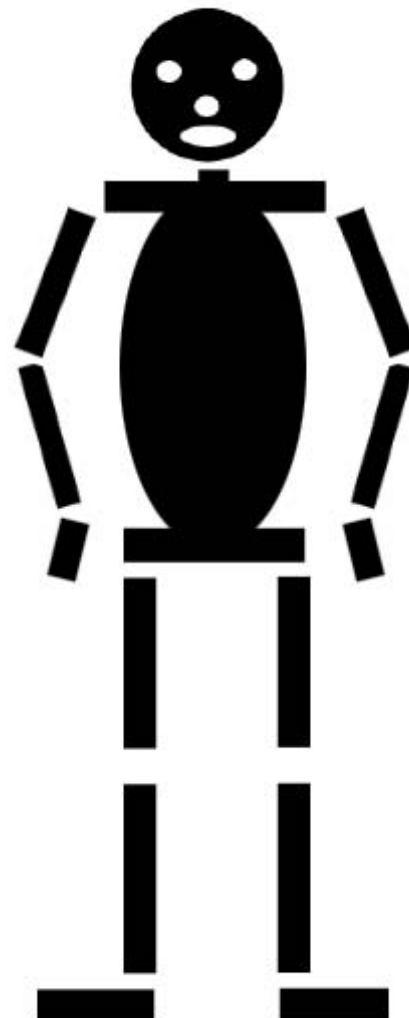
Doctor _____

Nurse _____

Care Coordinator _____

My Symptoms:

List from head to toe, circle or mark with an X on the drawing below



TRAINER'S TIP:

You may want to let participants know that in Module Three they will receive a Daily Planner handout to help with planning and to keep track of the tasks that are particularly difficult to remember. For now, distribute copies of the B3 handout “**When I Am Sick.**” Using an overhead transparency of this handout will probably be very helpful. Have the participants go from head to toe and note with words or an X or a circle the body part or area that is bothering them.

Keeping Track of Your Health

We also need to be aware of how we are feeling. We need to know the signs and symptoms of illness. One helpful way to think about this is to use a head to toe approach. Using the When I Am Sick handout, let's look at the diagram and talk about some of the concerns a person may have about their health. Let's start at the top of the head and move down.

How to Get the Medical Care You Need

You've all seen how things are supposed to work on TV shows about hospitals and emergency rooms. Things seem to go pretty smoothly - even when there are problems, everybody seems to know exactly the right thing to say or do so that the problem gets solved in the nick of time. Of course, it doesn't always work that way in real life. One reason is that in real life, we don't have scripts with all the lines written out and an ending already decided. But we can use some of the same techniques that go into a successful TV show.

You can't guarantee how things will turn out, but you'll have a much better chance of getting the information and care you need if you have a script or outline to follow. This is true for everyone - not just people with special health care needs. But it's especially important if you need extra time or other assistance. And just like actors playing a role, you will do better in the real situation if you practice ahead of time.

Let's look at the kinds of medical care most people need and how to get the most out of the healthcare providers you will see as a patient.

Everybody needs to have at least one doctor. Some people also need specialists who can help them with certain areas of their health. Just think about a few key questions:

- Who is your doctor?

- Who takes you to the doctor?
- How often do you go to the doctor?

You may be seeing a pediatrician now. Pediatricians take care of children and teens. If you're seeing a pediatrician, ask about when you will need to change to a doctor who takes care of adults. Also ask your pediatrician to give you the names of some doctors who see adult patients.

If you've been seeing a pediatrician and will be switching to a new doctor, consider whether you want to start seeing a family practice doctor or an internal medicine doctor. Internal medicine doctors see only adults.

If you have a family practice doctor right now, you may be able to keep seeing the same doctor, because family practice doctors see people of all ages. You may also want to talk with others about whether you should make a change.

If you also see specialists, you will need to find out if you can continue seeing them as you get older or if you need to change to a specialist who treats adult patients in that specialty area.

TRAINER'S TIP:

As you distribute the rest of the handouts for this module, you may want to spend extra time going through some or all of them and offering examples of how to use them. You probably don't need to take too much time on the **Questions for My Doctor**, but take time where you need to so that each is clear to your participants. After the handouts are all distributed - toward the end of the session - you should have enough time to let participants work in two's or three's to fill out some sample handouts for practice.

Managing Your Own Care

It's important for you to start managing your own care so you can be more involved in making decisions about your health. Two things you always need to keep in mind as important to managing your care are: be sure to tell your doctor how you are feeling and be prepared to ask questions. The next time you go to the doctor, you may want to write down a few things to say or ask. Take a look at the handout called **Questions for My Doctor**. These are the kinds of questions you may want to have ready for your next visit.

You may also want to write down some of the things your doctor says. To help you do this, we have a handout called **Visiting My Regular Doctor**. You may even ask to spend some time on your own with your doctor. Everyone has a right to have private conversations with their doctor. You should be able to ask about anything concerning your health. You may even have questions or concerns that you don't want to talk about in front of your parents. That's natural.

If you're going to be changing doctors, you'll want to meet the new doctor before you are actually sick so that you have a chance to see if you feel comfortable with this doctor, and so that the new doctor will know a little more about you. We have a handout to help you with this. It's called **Visiting a New Doctor**.

How many of you are already involved in making your own appointments? If your parents still do this, you may want to be around the next time to see how they do it. Then you may want to try it yourself. For those of you who already make your own appointments, or for those of you who are new at doing so, you may want to use the handout called **Making An Appointment**.

TRAINER'S TIP:

The Ordering Prescriptions and Refills handout will definitely need some time. You may even want to read it to your class members.

Now let's talk about medications. You may already be taking some. It's important for you to know what medications you need and when to take them. It's also important to be alert to side effects. Find out what side effects are possible with each of your medications. If you experience any of the side effects, tell your doctor right away.

You also need to know how to get a prescription filled and how to get refills. Let's take a little time to look at the handout called **Ordering Prescriptions and Refills**.

Next, let's think about how you'll get to your appointments. If you need to make special arrangements, you might want to use the handout called **Transportation for Medical Appointments**. Let's take a look.

Another helpful tool is a basic information sheet that you can post on your refrigerator or some other

highly visible place. Here is a handout called the **Emergency Information Card**. You can fill it out and put it where you can easily see and find it so that if you ever need to call 911, or go to an emergency room, you can quickly get it and take it with you for the emergency medical staff to read.

Practice Exercise

TRAINER'S TIP:

You are going to direct the participants to work with the handouts in groups. Be clear about which handouts they should work on, and in what sequence. Be sure you have extra copies of the ones they will work on, so that they can still take home clean copies for future use. Be available to circulate among the groups and help them out. You may want to have some names and situations ready that they can use for practice. Be sure to offer ideas and encouragement during the group discussion.

Let's take this time together as an opportunity to practice some of the situations we've talked about - situations like recognizing your symptoms, setting up an appointment, finding transportation, explaining how you are feeling, visiting your regular doctor or a new one, and being ready for an emergency. The handouts we've provided will guide you through the steps you can take to handle each of these situations.

Let's break up into two's or three's and practice how you might use these handouts. Together you can fill in the handout and figure out what you will say. Then we'll come together and share some of your scripts so we can all learn from one another.

We can even act some of them out. We want to use different names and change some of the facts to protect the confidentiality of your own personal situations. But we do encourage you to take blank handouts home with you and use them the next time you need an appointment. We'll take about 20 minutes to write the scripts and then we'll get back together.

Closing

So far, we've looked at the areas of self-awareness and physical health that are noted on our Healthy Lifestyle Habits diagram. We have two more areas to go, but this concludes our work for now. You are well on your way!

Thank you all for your effort and support of one another.

Module Three:

Emotional Health

TRAINER'S TIP:

You will need to have two copies of the **Daily Planner** (B13, Appendix B) for each participant - one to fill out in class and one to take home. For the Storyboard Exercise, use large sheets of flip chart paper to make up some blank storyboards by drawing several rows of boxes on each page, similar to a comic strip. The boxes have to be large enough for participants to draw in. Make plenty of copies for use in the exercise. You may want to have some standard-paper-size copies for them to take home as well. You can also use overhead transparencies of these handouts with an overhead projector. Bring along markers and tape. Have extra copies of the **Healthy Lifestyle Habits** handout (B5 in Appendix B), and an overhead for review.

To encourage active participation, you'll want to know something about the types of health care concerns participants bring with them. Then you can tailor examples and the discussion to those areas. You may need to make accommodations to allow everyone to participate in the group activities. For example, if an individual is unable to do the activity that involves drawing or writing, that person may be able to talk about the situation instead. You can group individuals so that participants can assist one another.

This session will be primarily working out the storyboard idea, so be prepared to do a lot of prompting. Make sure to circulate and make sure every group gets the necessary attention.

Welcome

Hello everyone. Do you all have the **Healthy Lifestyle Habits** handout? Let me know if you need a copy. In this module, we're going to turn our attention to the third part of our **Healthy Lifestyle Habits** - emotional health. It's every bit as important as physical health. In fact, our emotional health can directly affect our physical condition.

Emotional health has to do with our feelings about ourselves, our friends and family, and our work and leisure pursuits. It has to do with our feelings of happiness, contentment, frustration, anger,

sadness, safety and security. It has to do with our ability to cope with new and unexpected events. Such events frequently require that we make adjustments in our thoughts or behavior. Whether these events involve losses or happiness, they most often require some kind of adjustment.

We all need to make changes and adjustments in our lives. Fortunately, we can develop attitudes and skills that can help us in those times when change is necessary.

During such times, it's important for us to recognize our feelings and be able to communicate them. It's also important to get help if we are stuck in certain feelings, or if life seems to be getting out of control. Sometimes a school counselor, teacher, therapist, pastor, or rabbi can help or can provide direction on how to get help.

Exercise: Planning Helps Us Achieve Balance

To maintain our emotional health, it helps to have well-rounded interests and a balanced life. Keeping track of our activities and how we use our time can be a way of judging the balance in our lives.

- We want to have time alone and with others.
- We want to have time to work and time to have fun.
- Sometimes we need to challenge ourselves, and sometimes we need to kick back and relax.

Planning our time, planning to meet our needs instead of just letting things happen is useful for maintaining our emotional health. Let's look at one way you can get a handle on how you use your time. Let's make a sample schedule together so we can practice how to use the Daily Planner handout. Then you may want to try using it at home and see how it works for you.

Safety and Security

As the Healthy Lifestyle Habits handouts shows, self-awareness and self-protection are also necessary elements of emotional health. That means you need to be aware of safety and security.

Safety can mean anything from having a safe place to live to feeling safe around the people with whom we associate.

Safety requires that we follow cautious strategies - like not going out alone at night, wearing a seat belt in a car, and wearing safety equipment for sports. It also means avoiding risky behavior like drinking alcohol and smoking.

TRAINER'S TIP:

The issues of sexuality, privacy and domestic violence are certainly related to emotional health, but this workshop is not the place to deal with them. The Waisman Center's Healthy & Ready to Work series offers a special training guide and workshop on "Safety Awareness for Empowerment" developed by Dedra Hafner that could be mentioned to your participants. You can also refer them to *The Ethics of Touch* by Harber and Hinsburger listed in Appendix C

We also want to work toward healthy relationships with people. This involves knowing how to be open, but also how to have boundaries and protect ourselves. Be very clear about what kind of touching is appropriate for you - what we call "safe touch" — and about privacy. Each of us needs to be confident in knowing our boundaries and clearly communicating them. Sometimes this means asking for what we need. Sometimes it means saying "no."

Sometimes setting these boundaries is pretty clear-cut and sometimes it can be difficult. We may find ourselves involved in something that started out okay, but seems to be going somewhere we don't want to go. You should use your better judgment, and sometimes this means taking the time to stop and think rather than just doing something and regretting it later.

Storyboard Exercise

Let's explore the idea of having some answers to certain situations already spelled out before the situations actually happen. A good tool for us to use is what movie and TV directors call a storyboard. This is where the director draws a scene-by-scene picture of what will happen. We can do this same thing. It gives us a chance to think about possible ways a situation might occur and some ideas about how to handle the situation.

Here is an example of a storyboard situation: Ben was traveling along a sidewalk on his way to a small shopping mall. When he got to a busy intersection, he had to stop and wait for the traffic light to change. A young man approached him and asked him if he had some drugs.

Let's draw a picture of this situation. We don't have to be great artists, we can use stick drawings.

Now, let's draw some possible ways for Ben to react to this situation. One of the reasons this person may have approached him was because he uses a wheelchair, and so the person may have thought Ben would have some kind of prescription drugs that would have street value. This was an incorrect assumption. Of course, Ben was aware that being in the wheelchair, he had a limited ability to fend off certain physical threats.

One reaction would be to ignore the individual and cross the street as soon as the light changed. Then Ben wouldn't have to explain himself or get involved in an argument that might prolong the interaction. He could also have in mind that he is in a public place where he could call out for help if he needs to.

Storyboard Exercise

Find one or two partners to work with and let's practice drawing storyboards together. What are some situations that you have run into or heard about from others? If you can't think of one, let me know and I will give you some possible ideas. First, fill in the storyboard with pictures showing the situation. Then fill in another storyboard with the reaction you think would work best.

Then we'll get back together and share our ideas. We'll take about 15 - 20 minutes to work on this and then we'll share our storyboards with the whole group so we can all learn from each situation. I'll come around to help you, and keep track of the time so you don't have to worry about it.

Sharing and Discussion

Let's put up the large sheets of flip chart paper you have drawn your storyboards on and go through each one.

Now that we've learned how to do storyboards you can use this idea to prepare for new situations. You can also look back at problems you've had in the past and come up with better ways to handle these in the future. Actors go on to rehearse their scenes, and you can do the same thing.

Review and Closing

Once again, we've covered a lot of ground. But we've tried to give you tools that you can use in everyday life. To review, we've shown you how to use a schedule as a way of keeping track of your busy life and to feel good about the many things you are capable of accomplishing each day. We've also explored how to picture situations we may run into as a way to prepare ourselves in advance. Storyboards may also help us when we run into a problem and want to come up with new ways to react in the future.

The only area left for us to explore is the social piece of our healthy lifestyles model. That's what we'll turn our attention to in Module Four.

Thank you for your attention and good responses.

Module Four:

Networks of Support

TRAINER'S TIP:

This workshop uses the handout called **Paying for Health Care Fact Sheet** (B-12, Appendix B) plus some common items available in every community. Make copies of the handout and an overhead transparency to help review the information. The other items you will need are materials that can be used to help the youth get a better understanding of resources available. Specifically, you'll need copies of your local phone directory so that you can point out how to use the phone book to find resources. You can do the same with newspapers - and add in maps, visitor's guides, or other resource listings.

You will also revisit the **Healthy Lifestyle Habits** handout B5 in Appendix B and the **Health Care Checklist** B4. The review at the end offers the idea of drawing a gift-wrap bow on the graphic in the Healthy Lifestyle Habits handout. You can also get creative and work out how participants can put all of the workshop materials together in a box, gift wrap it, and put a bow on at the conclusion of the session.

Welcome

Hello again. In this session, we'll explore the social aspect of our **Healthy Lifestyle Habits**. Does anyone need a copy of that handout?

Our social lifestyle habits have to do with our place in our community, our social network. We are all part of both formal and informal social networks. Let's look at these networks in more detail and explore how they can contribute to our overall wellness.

Be aware that we're talking about something that is reciprocal. Social relationships are a two-way street. In all relationships, there is a give and take. We have something we get, but we also have something we give.

Formal Networks of Support

Let's look first at some of the formal networks of support. This includes government programs designed to help people with special health care needs be as independent as possible while also providing for certain basic necessities of life.

One of these programs involves the benefits available to some people through the Social Security Administration, called SSI. By qualifying for SSI, adults with disabilities may get a certain amount of money each month to help them cover some of the basic costs of living. They also receive Medical Assistance (also known as Medicaid) to help pay for their health care needs.

Be aware that there are special Social Security programs that allow someone who gets SSI to work and earn money without losing health care coverage. There are also some other ways adults can get their health care costs covered if they do not qualify for SSI. Let's review the handout called **Paying for Health Care Fact Sheet** to learn what these programs are in Wisconsin.

Making Decisions

In addition to SSI and other health care coverage programs, there are programs and resources that can help adults with disabilities find: jobs, additional education, assistance with living skills, and help with decision-making.

Some people are able to make their own decisions and some may need help only in specific areas (like financial decisions, for example). Other people may not really be able to make their own decisions and may benefit from having a guardian or someone who has power of attorney responsibilities to make decisions on their behalf.

A guardian is someone who is appointed by a judge after careful consideration of the person's capabilities and needs. A guardian can make decisions in some areas or all basic areas of another person's life. The guardian should be someone who has the best interests of the other person in mind. A guardian may be a full guardian or a limited one. Even a full guardian should allow some say in what is decided by the person they are guardian for. It's important for all people to have choices and some control in their lives.

If you do not have a guardian, you may have a representative payee or someone with power of attorney for finances to help you manage your money. There are also other possibilities like joint bank accounts.

If you do not have a guardian and are fully responsible for your own decisions, you are also responsible for the consequences of those decisions. Since you will be making your own health care decisions, it's very important for you to have something called a Durable Power of Attorney for Health Care. That means if you are too sick, or for some other reason cannot make a medical decision, you have named someone you trust who can legally make decisions and give permission for medical treatment. You can also have a Power of Attorney arrangement to help with decisions in other areas of your life instead of having a guardian. You will want to talk with your parents or some other adult you trust about how you will set up your decision-making alternatives.

Creating an Informal Support Network

Being independent does not mean that you have to do everything alone. Almost everyone looks for advice and input from others in making big decisions. All of us need help from time to time. Sometimes we need some good advice. Sometimes we need more information. Sometimes we need someone who can help us think through a problem. Family and friends can help us, but there are also other resources such as independent living centers or other advocacy organizations that have specially trained staff who are able to offer information and assistance.

TRAINER'S TIP:

In this next section, you will lead the class in creating several lists: support people, possible jobs, volunteer possibilities and hobbies. You'll be writing their responses on your flip chart.

Let's get a picture of some of the people who are part of our support network. Let's take a few minutes for each of you to list at least some of the names of important people in your lives.

Some of our community involvement happens through the work we do. Most people find it important to have some kind of meaningful work. Have you thought about the kind of job you may want to have? What are some job possibilities?

Let's brainstorm a list of possible jobs you could consider in your community. Call out some ideas and we'll write them on the flip chart.

Another way of having meaningful work may also be volunteering. Some people do volunteer work instead

of a job, and some do volunteer work in addition to a paid job. **What are some of the kinds of volunteer opportunities that you know of in your community?** Let's make another list.

These lists may have given you some ideas to pursue in the future. The people in your circle of support may also have ideas about who might help you learn about employment and volunteer possibilities. Over time, you may even add more people to your circle of support.

Meeting new people and continuing to develop new interests is also important to your social health.

If you're bored, you can always develop a new hobby. There are so many kinds of hobbies and leisure activities to explore that there is literally something for everyone. Let's make a quick list of hobbies you know about; then we'll add a few you may not have thought of before.

Finding Resources

Every community offers resource possibilities. Let's talk about our community and how to find ways to be more involved, meet new people, and learn new things. As a tool for our discussion, **let's use the phone book** and see how many possibilities we can find. Let's go to some key areas in the phone book and see what they offer. You can find organizations, clubs, churches and schools offering different classes (and more) in the phone book. There is also a map in the phone book or from the local visitor's bureau.

TRAINER'S TIP:

You will essentially be showing your participants how to use a phone book and the newspaper to find useful resources. Be sure you have familiarized yourself with what you want them to learn. Feel free to add any information you may have on the subject of resources.

Another resource may be your public library.

Librarians are trained to help people do research. You may be able to find books, videos, workshops and discussion groups through your library. Ask your local reference librarian for help. Most libraries also have computers available to the public, and many offer help on how to use them.

Another tool can be the newspaper. Let's look at what you can find in the newspaper by going through a daily paper and a Sunday edition. Many communities have an annual resource edition that you may want to save and use throughout the year.

Review and Summary

Let's review our **Healthy Lifestyle Habits** handout and some of what we have learned together. We can remind each other of what each square stands for and what is included in it.

Let's also go back to the **Health Care Checklist** you filled out when we started and see how much you've learned. You may have some key areas you want to work on. Pick one or two things you want to begin with and figure out your first steps for each of those.

You may even want to do some planning for the future that looks at areas beyond health care. There are several ways to do what is called "Future Planning." Some of these ways involve getting together with other people in your life and coming up with ideas for goals and interests you would like to pursue, how to make a plan for moving ahead, and how to involve others in helping you succeed. There are workbooks and organizations that can help you do this. For more information see *PATH: A Workbook for Planning Possible Positive Futures* or *Planning for Adolescents with Special Health Care Needs and Disabilities*, both listed under Health and Lifestyle resources in (Appendix C.)

A Literal Wrap Up

Now let's go back to our **Healthy Lifestyle Habits** diagram. It looks like a square or a box. Let's see what happens when we put a bow on top of the box. Now it is not just a box but instead, it looks more like a present.

Healthy Lifestyle Habits can be challenging, but instead of thinking of them as a chore, we want you to think of them as a gift you give yourself. By developing healthy lifestyle habits, you will be in a better position to do the things you want to do in your life, feel good about yourself and others - and have some fun along the way!

Appendix A

Handouts for Parent Workshop

- A1** Rules of 18
- A2** Transition to Adult Life: Knowledge of the Game
- A3** Daily Planner
- A4** A Parent's Health Care Check List
- A5** Player Profile Interview Format
- A6** Making An Appointment
- A7** Emergency Information Card
- A8** Ordering Prescriptions and Refills
- A9** Transportation for Medical Appointments
- A10** Visiting a New Doctor
- A11** Visiting My Regular Doctor
- A12** Team Roster
- A13** When I am Sick
- A14** Health Care Financing Fact Sheet
- A15** Your Coaching Resume



A1

Rules of 18

In Wisconsin, when a person reaches his or her 18th birthday, he or she legally becomes an adult. Ability or disability does not matter. Upon reaching the age of 18, all the rights of legal adulthood are in effect (except for drinking beer or alcohol. This is not a right until age 21). Some of these rights include the ability to:

- Vote;
- Get married;
- Make a will;
- Make a contract (rent an apartment, buy a car, take out a loan);
- Give or refuse consent for medical treatment;
- Make independent decisions free from parental control; and
- Apply for credit

There are also responsibilities that come along with these rights. Some of these responsibilities include:

- Being tried in adult criminal court; (This actually begins at age 17 and, in some circumstances, can occur as young as age 14 if the individual is “waived” into adult court.)
- Self support; (Parents are not required to support their adult children.)
- Serving on Jury Duty if called to do so;
- Being held liable for contracts entered into; and
- **REGISTERING FOR THE DRAFT.** It does not matter if someone is capable of serving or not. EVERY male citizen and alien residing in the United States must register within 30 days of his 18th birthday. Even a male with severe disabilities must register, although there may be no way he can serve. Failure to register for the draft is a federal crime.

Parents must understand that they do not continue to have decision-making authority for their adult child after that child turns 18. Even in cases of severe disability, adults are presumed able to act on their own behalf unless a court of law decides otherwise.

There are options for individuals who need assistance with decision-making. Guardianship is the most widely known option, but there are other possibilities.

Guardianship can be established for an individual who lacks the mental capacity to make informed decisions about his or her own care or finances. Physical disability and/or making poor decisions without actual mental incapacity are not enough to require guardian.

A1 continued

There are different types of guardianship. Full guardianship may not be needed. Sometimes a limited guardianship can be established so that the individual with a disability can retain some rights. The types of guardians include: Guardian of the Person, Guardian of the Estate, Temporary Guardian, Limited Guardian, Standby Guardian and Successor Guardian. Parents do not necessarily need to serve as their adult child's guardian. A friend, another family member or a volunteer guardian appointed by the judge can assume this role.

Another option to consider may include utilizing Power of Attorney. Having a Representative Payee for financial matters may be sufficient. Parents must get good information to make informed decisions in this area and discuss these issues with their teen to the greatest extent possible. As in other areas of life, the least restrictive option possible deserves serious consideration.

Information for this handout was obtained from:

- “Guardianship of Adults: A Decision-Making Guide for Family Members, Friends and Advocates,” a handbook by Roy Froemming, J. D., and Betsy Abramson, J. D. It is available from the Department of Health and Family Services. Division of Supportive Living, ATTN: Publications Order, One West Wilson St., P. O. Box 7851, Madison, WI 53707-7851. Include the publication number (PSL-460), your name, address and a phone number in case of questions.
- “On Being 18,” by Attorney David E. McFarlane, published by the State Bar of Wisconsin, 5302 Eastpark Blvd., P. O. Box 7158, Madison, WI 53707-7158. Phone number: (608) 257-3838.
- The Wisconsin Guardianship Support Center, Elder Law Center, Coalition of Wisconsin Aging Groups, 2850 Dairy Drive, Suite 100, Madison, WI 53718-6751. Phone number: (608) 224-0660 or toll free at 1-800-488-2596.
- Wisconsin Coalition for Advocacy, 16 North Carroll Street, Suite 400, Madison, WI 53703. Phone number: (608) 267-0214 or toll free at 1-800-928-8778.

A2

Transition to Adult Life: Knowledge of the Game

- Nearly 33% of children/youth in the U.S. have a form of chronic illness.
- Up to 90% of these youth will survive into adulthood.
- Almost 25,000 full-time college freshmen identified themselves as having a health-related disability (16% of total college freshmen).

Source:

Massachusetts Department of Public Health, 2000

“All the art of living lies in a fine mingling of letting go and hanging on.”

--Havelock Ellis

Teens and young adults with special health care needs should be able to:

1. Understand their own condition and the treatment or intervention needed.

“I have cerebral palsy because I lost oxygen at birth...I need help with...”

2. Explain their condition and needed treatment or intervention to others.

“I am on three medications for spasticity.”

3. Monitor their health status on an ongoing basis.

“I use my communication device to let others know how I am feeling.”

4. Ask for guidance from their pediatric health care providers on how and when to make the move from pediatrics to adult care.

“I’m going to ask my pediatrician when should I start seeing a family practice doctor for my general care instead of a pediatrician.”

5. Learn about the systems that will apply to them as adults, such as health insurance (private or medical assistance) and its importance, social security and other programs, as well as issues like guardianship and power of attorney for health care.

“I have applied for medical assistance through Social Security for now because I have a disability and I need to be able to get medical care.”

6. Identify both formal and informal advocacy services and supports they may need in order to be as independent as possible but utilize trusted advisors/mentors.

“I ask my parents for advice because they have known my medical care the longest.”

“Experience is the name everyone gives to their mistakes.”
--Oscar Wilde

How do we prepare our teens to meet the challenges of adult health care? By using ordinary, every day teaching opportunities and lots of practice.

“Just because a thing is inconceivable doesn’t mean it’s impossible.”
--Lewis Carroll

Start small. Start slow. Start now!

A3

Daily Planner

TIME	ACTIVITY/WHERE/WHO	SPECIAL REMINDERS

A4

A Parent's Health Care Check List

QUESTION	YES	NOT YET	FIRST STEPS
Do I know how my teen learns best?			
Can my teen describe his/her special health care needs?			
Do we discuss and demonstrate healthy lifestyle habits as a family?			
Can my teen name his/her doctor?			
Can my teen communicate that he/she is feeling ill?			
Can my teen describe symptoms when feeling ill?			
Do we use a family calendar for tracking appointments, activities, etc.?			
Is my teen involved when I schedule appointments?			
Can my teen schedule appointments on his/her own?			
Do I encourage my teen to give information and answer questions at appointments?			
Have I discussed transitioning to adult care providers with my teen's present providers?			
Do I involve my teen in registering or checking in for appointments (showing insurance/MA card)?			
Does my teen know the medications he/she is taking, the reason, schedule and pertinent side effects?			
Do I involve my teen in filling and refilling prescriptions?			

A4 continued

A Parent's Health Care Check List

QUESTION	YES	NOT YET	FIRST STEPS
Is my teen involved in maintaining/ordering monthly supplies, equipment or scheduling home care?			
If my teen is on my insurance, do I know how long this can continue?			
Do I know what insurance or health care coverage will be available to my teen when he/she turns 18?			
Have we talked about and made plans for guardianship (none, full, limited)?			
Have we discussed and planned for Power of Attorney for Health Care?			
Do I use formal and/or informal advocacy or supports and is my teen aware of this?			

A5

Player Profile Interview Format

Write a one- or two-sentence description of your player. _____

Briefly describe your player's special health care needs. _____

Briefly describe any of your player's special talents or abilities. _____

Briefly describe how your player learns best. _____

Describe how this player contributes to your family team. _____

Describe your goals for this player's involvement or independence in his/her life. _____

A6

Making An Appointment

When you call to make an appointment, you need to have some basic information ready. You should also have your calendar. Fill in as many of the blanks on this form as you can before you make your call. Then you can use it as an outline when you do call. The person answering the phone may be able to help you or may need to transfer your call to someone else. If that happens, you may have to repeat some of the same information.

Place your call using this phone number _____

Hello, my name is _____

I need an appointment to see _____

because _____

(for example: check-up, don't feel well, back pain...)

How soon can I get in?

(write the date and time you are told here _____)

(If that time is okay, say you'll take the appointment.)

(If it is not, ask for another date and/or time. _____)

How long is the appointment?

(write the amount of time here _____)

(If you will need more time be sure to say so and how much)

OK, my appointment is _____ for _____

(write the date, time and for how long and repeat it back to be sure)

(If you will need a lift or help to get onto the exam table or other accommodations, what you will need _____)

Thank you.

Just in Case: You might need your Date of Birth _____ Phone Number _____

MA or Insurance Number _____

A7

Emergency Information Card

Name _____

Date of Birth _____

Address _____

Allergies to Latex or Medications:

Phone Number _____

Emergency Contacts

1) Name _____

Primary Doctor _____

Phone Number _____

Phone Number _____

Relationship _____

Hospital/Clinic _____

2) Name _____

Pharmacy Name _____

Phone Number _____

Phone Number _____

Relationship _____

Insurance or MA Number _____

Special Needs Information:

Chronic Illnesses/Disabilities/Communication/Equipment/Other _____

See the back of this page for medications and other information

A7 continued

Medication Information

Medications

Name _____ Dose _____

Name _____ Dose _____

Name _____ Dose _____

Name _____ Dose _____

Name _____ Dose _____

Name _____ Dose _____

Name _____ Dose _____

Name _____ Dose _____

Name _____ Dose _____

Name _____ Dose _____

Recent Illnesses/Surgeries/Hospitalizations _____

Living Will? If Yes, Where? _____ No _____

Power of Attorney for Health Care?

If Yes, Who? _____ No _____

Phone Number _____

Guardian? If Yes, Who? _____

Phone Number _____

A8

Ordering Prescriptions and Refills

When your doctor wants you to take medication, the prescription may be called in to a pharmacy and you will pick it up. If the doctor gives you a written prescription, you will take it to your pharmacy to get it filled. If there are refills ordered so that you will continue to take the medication, you will need to order refills so you don't run out of the medication. To order a refill on a medication you already have, use the information on your medication bottle. Have the bottle with you or write the information in the blanks on this form before you make your phone call. You can then use this form as an outline for your call. The phone number of the pharmacy is usually on the label on the medication bottle. Take your insurance or MA card when you go to get your medicine.

Pharmacy Phone Number _____

Hello, my name is _____

I need a refill on a prescription.

The prescription number is _____

(This number is usually on the upper right of the label on the bottle)

The name of the medication is _____

When can I pick it up? _____

Can you deliver it? _____ If yes, when? _____

Is there a co-pay? (How much?) _____

Thank you.

When you call the pharmacy, a person may answer and take the information. Sometimes you may get an answering system that tells you how to give the information the pharmacy needs by pushing certain numbers on the phone. If this is too hard or too confusing, you can usually stay on the phone or push a number given to get help from a person who will take the information from you. The number of refills is usually on the lower left part of the label on the medication bottle. If you don't have any more refills left, but still need the medication, the pharmacy will usually call your doctor to get a new prescription. Call to order refills on your medication when you have one week of medicine left, so you don't run out on a weekend, holiday or while on a trip. Mark your calendar to remind yourself of when to re-order.

Make sure you understand how to take your medication and any side effects that might happen. You will get written information when you pick up your medication, but ask the pharmacist any questions you may have. If you get home and have a question or concern, call and ask the pharmacist for information over the phone. You can also call your doctor's office and ask to speak to your doctor's nurse. Nurses can also answer a lot of your questions and can check with your doctor if needed.

A9

Transportation for Medical Appointments

If you need to set up transportation for your appointments, you may be calling a friend or someone else who drives you places. You may be calling a transportation service. Be sure you call right after you make your appointment to avoid problems. You can fill in the blanks on this form and use it as an outline when you make your call. If you need a ride after the appointment, say so in the same call.

Name of driver or service _____

Phone number _____

(If you're not sure who to call, ask your parents or your case manager).

Hello, this is (_____). I need a ride to get to an appointment.

The date and time are _____

I am going to _____

(Give the name and address).

You would need to pick me up at _____

(Address).

Can you do this? _____ Yes _____ No

(If yes, ask) "What time will you pick me up?" _____

(Write the time here).

(If no, ask) "Who else can I call?" _____

I also need a ride home after the appointment.

Who do I call if there is a problem? _____

(Name and phone number).

Do I need any paperwork or money? _____

(Write the answer here).

Thank you.

A10

Visiting a New Doctor

Name _____

Why I am here: _____

This is my medical history: _____

These are my medical conditions: _____

Medications and medication allergies: _____

Other allergies: _____

A10 continued

Past surgeries/hospitalizations: _____

Other doctors I have seen: _____

How I communicate best: _____

Other things to know about me: _____

What should I know about you? _____

A11

Visiting My Regular Doctor

This is a form to use while you are at an appointment

Doctor's Name _____ Date _____

Why I am here: _____

Information that is important for me to remember: _____

Do I need any medical tests? _____

(Write them here).

Do I need any new medication? _____

(Write them here).

Do I need another appointment? _____

(If yes, write when here).

Team Roster

MANAGER	
COACH	
ASSISTANT COACHES	
POSITION COACHES	
TEAMMATES	
CHEERLEADERS	

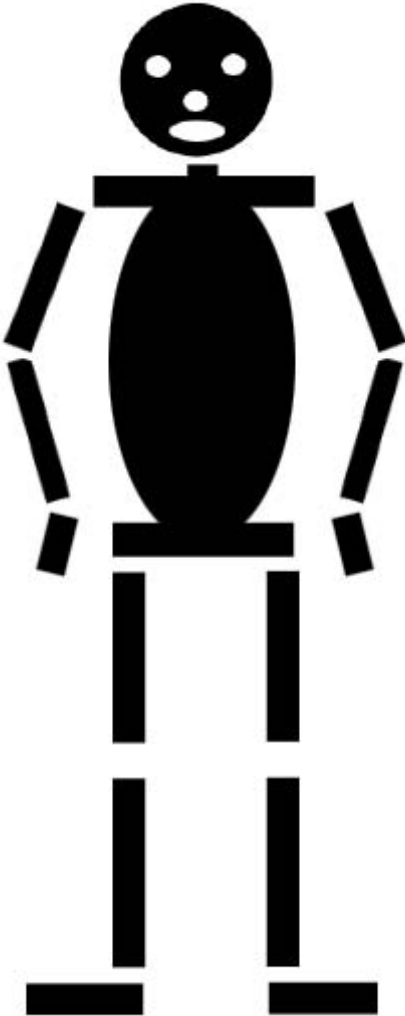
A 13

When I am Sick

Doctor's Name _____ Date _____

My symptoms:

List from head to toe, circle or mark with an X on the drawing below



A13 *continued*

Questions For My Doctor

What is wrong? _____

What should I do? _____

How long will it last? _____

When should I start to feel better? _____

Can I go to work/school? _____

Are there things I can't do? _____

Do I need medicine? _____

How much, how often? _____

Are there side effects? _____

What should I do if I don't start feeling better or if I feel worse? _____

A14

Health Care Financing Fact Sheet

Health care is expensive. Teens and young adults need to know how they will meet the cost of their health care as adults. Families need to think about family insurance limits, types of health insurance coverage and ways eligibility is determined. Attention also needs to be given to learning about other possible resources and how to access them. Knowledge of health benefits counseling and advocacy services may also be extremely important. While this fact sheet provides some basic information, it is only a start and each individual situation needs to be explored in a comprehensive and detailed manner.

Family Insurance

If the teen has been covered under the parent's private insurance, careful attention must be given to what happens when the teen becomes an adult (age 18). Parents need to read their policies carefully, before their teen reaches 18, in order to make effective decisions. Some policies allow the adult child to continue coverage if he or she is a full time student. Some policies put additional conditions on continued coverage. Some policies will allow some continued coverage up to age 21 or 25. Some will allow indefinite continued coverage for adult children if they are disabled (according to the Social Security Administration's definition) and if the parent continues to provide 50% or more of that adult child's support and maintenance. This must be considered carefully if the child will be receiving Supplemental Security Income (SSI) because some aspects of SSI payments are based on the adult child no longer being claimed as a dependent by the parents, while others will allow the parents to continue to support the individual at a higher level. In Wisconsin, SSI is paired with the medical assistance (MA) benefit. For children on the Katie Beckett program, at 18 they may be eligible for SSI to keep the MA benefit.

An adult child who no longer qualifies for continued coverage under their parent's insurance plan can continue to get coverage for a period of time under a current insurance plan by paying the individual premiums. This is known as COBRA coverage. A young adult may continue coverage under COBRA for up to 36 months after leaving the parent's health insurance plan due to losing their status as a dependent. This must be put in place at the time coverage is scheduled to cease and can be quite costly, but it may prevent the 63-day lapse in coverage that might disqualify future insurance coverage due to a pre-existing condition. Even though the monthly premiums may be expensive, this may prove to be a short-term solution. If the health and dental plans are separate, each should be considered based on its own cost and potential value. For example, given some of the current problems with MA recipients receiving dental care, continuing to carry just the dental plan may be affordable and very beneficial.

BadgerCare

A young adult who does not have access to insurance through some other means can apply for BadgerCare at age 18. He or she can be covered under that program until the 19th birthday. This may, again, be a short-term solution until another option can be found.

Katie Beckett Program

Parents should be aware that if their child is now receiving Medical Assistance through the Katie Beckett Program and continues to qualify based on their disability, that coverage continues until the child's 19th birthday. Parents should receive a letter from the state explaining this before the child's 18th birthday.

A14 continued

Disability Evaluation

If a child has been receiving Medical Assistance through Social Security due to a disability, a new disability determination will have to be made to continue receiving this benefit as an adult. A written notice will be sent around the child's 18th birthday. Continued disability status is not automatic. Similarly, if your child has not qualified for some programs, like the Katie Beckett Program, it may be worthwhile for him or her to apply for coverage through Social Security. There are a number of Social Security programs for people with disabilities. One is the Plan for Achieving Self Support (PASS). This program allows an adult with SSI to exclude some income and assets that would usually be considered. The goal is to help people with disabilities pursue work without losing their healthcare coverage.

References:

ABC for Health, a health benefits information and advocacy agency. Contact ABC for Health at 1-800-585-4222 or www.abcforhealth.org

Additional information about Social Security options can be obtained by contacting your local Social Security Office or by visiting www.ssaa.gov/pubs/10029.html

Contact the Wisconsin Department of Health and Family Services at www.dhfs.state.wi.us

A15

Your Coaching Resume

List a few of the transitions you've already been through.

Briefly describe what got you through those experiences.

What have you learned about yourself that you didn't know before you had your child with special health care needs?

A15 continued

Briefly describe how you like to learn new things.

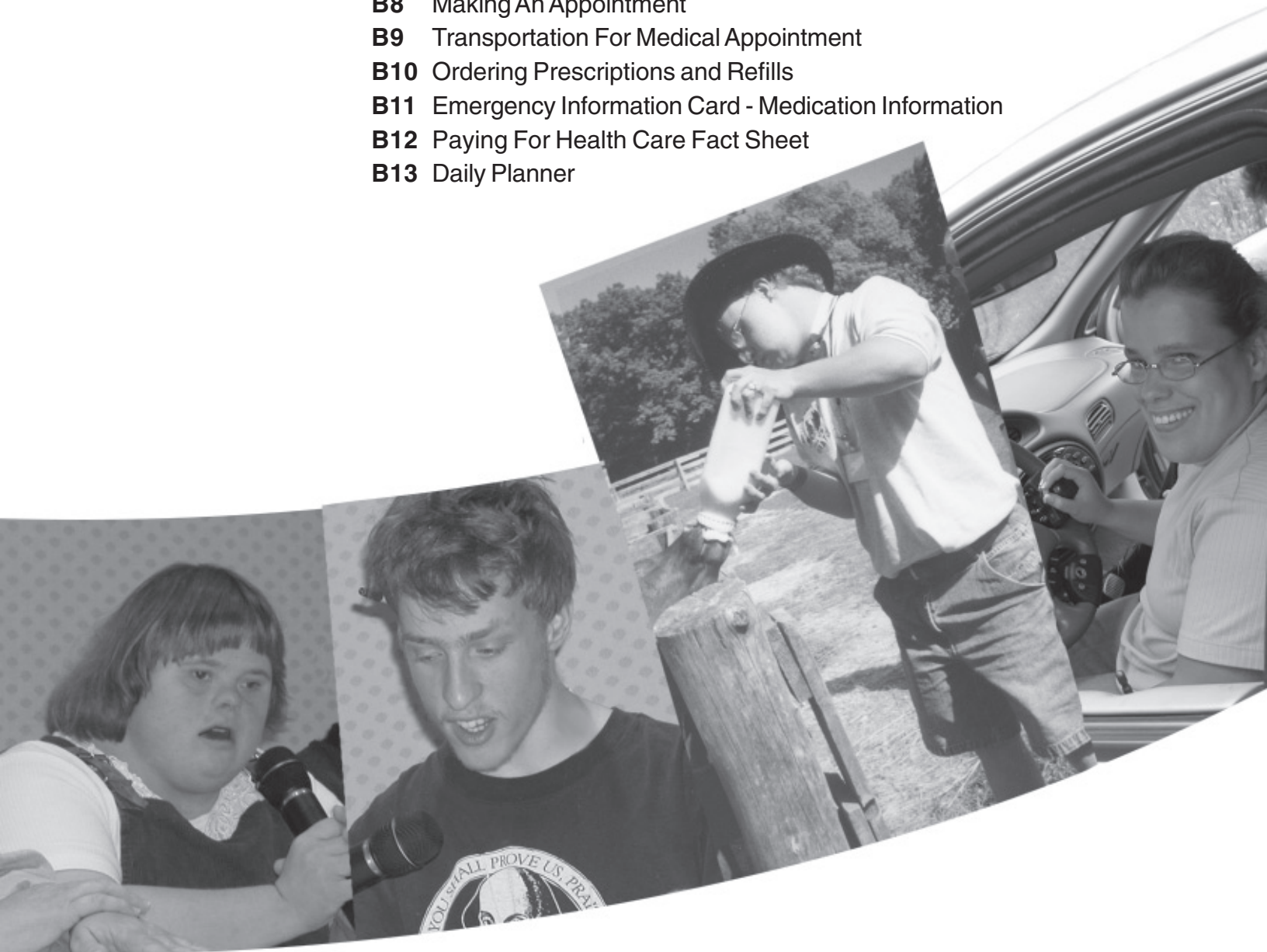
What helps you feel good about yourself and helps to keep you going?

List something you've always wanted to do but haven't gotten around to doing yet.

Appendix B

Handouts for Teen and Young Adult Workshop Series

- B1** About Me
- B2** Rules of 18
- B3** When I am Sick
- B4** Health Care Checklist
- B5** Healthy Lifestyle Habits
- B6** Visiting My Regular Doctor
- B7** Visiting a New Doctor
- B8** Making An Appointment
- B9** Transportation For Medical Appointment
- B10** Ordering Prescriptions and Refills
- B11** Emergency Information Card - Medication Information
- B12** Paying For Health Care Fact Sheet
- B13** Daily Planner



B1

About Me

Describe yourself in one or two sentences. _____

What are you good at? _____

List some things you like. _____

List some things you don't like. _____

Describe your special health care needs. _____

B1 *continued*

Describe how you learn best. _____

Describe how you contribute to your family. _____

What are your goals for your life? _____

B2

Rules of 18

In Wisconsin, when a person reaches his or her 18th birthday, he or she legally becomes an adult. Ability or disability does not matter. Upon reaching the age of 18, all the rights of legal adulthood are in effect (except for drinking beer or alcohol. This is not a right until age 21).

Some of these rights include the ability to:

- Vote;
- Get married;
- Make a will;
- Make a contract (rent an apartment, buy a car, take out a loan);
- Give or refuse consent for medical treatment;
- Make independent decisions free from parental control; and
- Apply for credit

There are also responsibilities that come along with these rights. Some of these responsibilities include:

- Being tried in adult criminal court; (This actually begins at age 17 and, in some circumstances, can occur as young as age 14 if the individual is “waived” into adult court.)
- Self support; (Parents are not required to support their adult children.)
- Serving on Jury Duty if called to do so;
- Being held liable for contracts entered into; and
- **REGISTERING FOR THE DRAFT.** It does not matter if someone is capable of serving or not. EVERY male citizen and alien residing in the United States must register within 30 days of his 18th birthday. Even a male with severe disabilities must register, although there may be no way he can serve. Failure to register for the draft is a federal crime.

Parents must understand that they do not continue to have decision-making authority for their adult child after that child turns 18. Even in cases of severe disability, adults are presumed able to act on their own behalf unless a court of law decides otherwise.

There are options for individuals who need assistance with decision-making. Guardianship is the most widely known option, but there are other possibilities.

Guardianship can be established for an individual who lacks the mental capacity to make informed decisions about his or her own care or finances. Physical disability and/or making poor decisions without actual mental incapacity are not enough to require guardian.

There are different types of guardianship. Full guardianship may not be needed. Sometimes a limited guardianship can be established so that the individual with a disability can retain some rights. The types of guardians include: Guardian of the Person, Guardian of the Estate, Temporary Guardian, Limited Guardian, Standby Guardian and Successor Guardian. Parents do not necessarily need to serve as their adult child's guardian. A friend, another family member or a volunteer guardian appointed by the judge can assume this role.

Another option to consider may include utilizing Power of Attorney. Having a Representative Payee for financial matters may be sufficient. Good information is needed to make informed decisions in this area. As in other areas of life, the least restrictive option possible deserves serious consideration.

Information for this handout was obtained from:

- "Guardianship of Adults: A Decision-Making Guide for Family Members, Friends and Advocates," a handbook by Roy Froemming, J. D., and Betsy Abramson, J. D. It is available from the Department of Health and Family Services, Division of Supportive Living, ATTN: Publications Order, One West Wilson St., P. O. Box 7851, Madison, WI 53707-7851. Include the publication number (PSL-460), your name, address and a phone number in case of questions.
- "On Being 18," by Attorney David E. McFarlane, published by the State Bar of Wisconsin, 5302 Eastpark Blvd., P. O. Box 7158, Madison, WI 53707-7158. Phone number: (608) 257-3838.
- The Wisconsin Guardianship Support Center, Elder Law Center, Coalition of Wisconsin Aging Groups, 2850 Dairy Drive, Suite 100, Madison, WI 53718-6751. Phone number: (608) 224-0660 or toll free at 1-800-488-2596.
- Wisconsin Coalition for Advocacy, 16 North Carroll Street, Suite 400, Madison, WI 53703. Phone number: (608) 267-0214 or toll free at 1-800-928-8778.

B3

When I am Sick

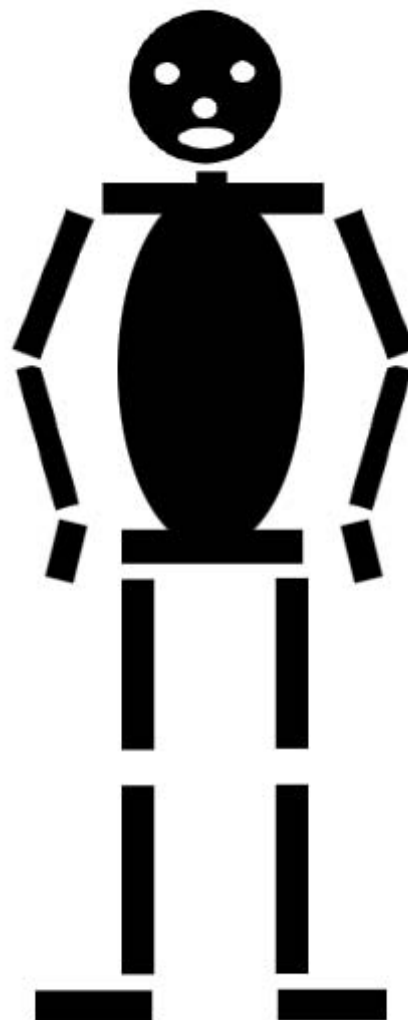
Doctor's Name _____ Nurse _____

Care Coordinator _____

Phone Numbers _____

My Symptoms:

List from head to toe, circle or mark with an X on the drawing below



Questions For My Doctor

What is wrong? _____

What should I do? _____

How long will it last? _____

When should I start to feel better? _____

Can I go to work/school? _____

Are there things I can't do? _____

Do I need medicine? _____

How much, how often? _____

Are there side effects? _____

What if I don't start feeling better or I feel worse? _____

B4

Health Care Checklist

QUESTION	YES	NOT YET	FIRST STEPS
Do I know how I learn best?			
Can I describe my special health care needs?			
Do we discuss and demonstrate healthy lifestyle habits as a family?			
Can I name my doctor(s)?			
Can I tell when I'm getting sick?			
Can I describe my symptoms when I'm sick?			
Do we use a family calendar for tracking appointments, activities, etc.?			
Can I make my own appointments?			
Can I arrange transportation to appointments?			
Do I give information and answer questions at appointments?			
Have I discussed transitioning to adult care providers with my present providers?			
Do I know how to register or check in for appointments (i.e., showing insurance/MA card)?			
Do I know the medications I am taking, the reason(s), schedule, and pertinent side effects?			

QUESTION	YES	NOT YET	FIRST STEPS
Do I know how to fill and refill prescriptions?			
If I am on my parent's insurance, do I know how long this can continue?			
Do I know what insurance or health care coverage will be available when I turn 18?			
Have we talked about and made plans for guardianship (none, full, limited)?			
Have we discussed and planned for Power of Attorney for Health Care?			
Do I know how to use formal or informal advocacy or supports?			

B5

Healthy Lifestyle Habits

<p>Diet and Exercise</p> <p>Healthy eating habits</p> <p>Controlling weight</p> <p>Having enough energy</p> <p>Personal appearance (Grooming and clothes)</p>	<p>Balance</p> <p>Understanding stress</p> <p>Work and leisure</p> <p>Challenge and relaxation</p> <p>Alone and with others</p>
<p>Healthy Relationships</p> <p>Friends vs. acquaintances</p> <p>Social networks (clubs, church, sports teams, etc.)</p> <p>Activities vs. hanging out</p>	<p>Self-Awareness and Self Protection</p> <p>Avoiding risky behaviors</p> <p>Safety practices</p> <p>Privacy and boundaries</p> <p>Feelings and emotions</p>
<p>Healthy Lifestyle Habits are a gift we give ourselves</p>	

B6

Visiting My Regular Doctor

This is a form to use at an appointment.

Doctor's Name _____ Date _____

Why I am here: _____

Information that is important for me to remember: _____

Do I need any medical tests? _____
(Write them here).

Do I need any new medication? _____
(Write them here).

Do I need another appointment? _____
(If yes, write when here).

B7

Visiting a New Doctor

Why I am here: _____

This is my medical history: _____

These are my medical conditions: _____

Medications and medication allergies: _____

Other allergies: _____

Past surgeries/hospitalizations: _____

Other doctors I have seen: _____

How I communicate best: _____

Other things to know about me: _____

What should I know about you? _____

B8

Making An Appointment

When you call to make an appointment you need to have some basic information ready. You should also have your calendar. Fill in as many of the blanks on this form as you can before you make your call. Then you can use it as an outline when you do call. The person answering the phone may be able to help you or may need to transfer your call to someone else. If that happens, you may have to repeat some of the same information.

Place your call using this phone number _____

Hello, my name is _____

I need an appointment to see _____

because _____
for example: check-up, don't feel well, back pain...)

How soon can I get in?
(write the date and time you are told here _____)

(If that time is okay, say you'll take the appointment.)
(If it is not, ask for another date and/or time. _____)

How long is the appointment?
(write the amount of time here _____)
(If you will need more time be sure to say so and how much)

OK, my appointment is _____ for _____
(write the date, time and for how long and say it back to be sure)

(If you will need a lift or help to get onto the exam table or other accommodations what you will need _____)

B9

Transportation for Medical Appointments

If you need to set up transportation for your appointments you may be calling a friend or someone else who drives you places. You may be calling a transportation service. Be sure you call right after you make your appointment to avoid problems. You can fill in the blanks on this form and use it as an outline when you make your call.

If you need a ride after the appointment say so in the same call.

Name of driver or service _____

Phone number _____

(If you're not sure who to call, ask your parents or your case manager).

Hello, this is _____. I need a ride to get to an appointment.
(give your first and last name)

The date and time are _____

I am going to _____
(Give the name and address).

You would need to pick me up at _____
(Address).

Can you do this? _____ Yes _____ No

(If yes, ask) "What time will you pick me up?" _____
(Write the time here).

(If no, ask) "Who else can I call?" _____

I also need a ride home after the appointment.

Who do I call if there is a problem? _____
(Name and phone number).

Do I need any paperwork or money? _____
(Write the answer here).

Thank you.

B10

Ordering Prescriptions and Refills

When your doctor wants you to take medication, the prescription may be called in to a pharmacy and you will pick it up. If the doctor gives you a written prescription, you will take it to your pharmacy to get it filled. If there are refills ordered so that you will continue to take the medication, you will need to order refills so you don't run out of the medication.

To order a refill on a medication you already have, use the information on your medication bottle. Have the bottle with you or write the information in the blanks on this form before you make your phone call. You can then use this form as an outline for your call.

The phone number of the pharmacy is usually on the label on the medication bottle. Take your insurance or MA card when you go to get your medicine.

Pharmacy Phone Number _____

Hello, my name is _____
I need a refill on a prescription.

The prescription number is _____
(This number is usually on the upper right of the label on the bottle)

The name of the medication is _____

When can I pick it up? _____

Can you deliver it? _____ If yes, when? _____

Is there a co-pay? (How much?) _____

Thank you.

B10 *continued*

When you call the pharmacy, a person may answer and take the information. Sometimes you may get an answering system that tells you how to give the information the pharmacy needs by pushing certain numbers on the phone. If this is too hard or too confusing, you can usually stay on the phone or push a number given to get help from a person who will take the information from you.

The number of refills is usually on the lower left part of the label on the medication bottle. If you don't have any more refills left, but still need the medication, the pharmacy will usually call your doctor to get a new prescription.

Call to order refills on your medication when you have one week of medicine left, so you don't run out on a weekend, holiday or while on a trip. Mark your calendar to remind yourself of when to re-order.

Make sure you understand how to take your medication and any side effects that might happen. You will get written information when you pick up your medication, but ask the pharmacist any questions you may have.

If you get home and have a question or concern, call and ask the pharmacist for information over the phone. You can also call your doctor's office and ask to speak to your doctor's nurse. Nurses can also answer a lot of your questions and can check with your doctor if needed.

B11

Emergency Information Card

Name _____ Date of Birth _____

Address _____

Allergies to Latex or Medications: _____

Phone () _____

Emergency Contacts:

1) Name _____ Relationship _____

Phone Number _____ Primary Doctor _____

Relationship _____ Phone Number _____

2) Name _____ Hospital/Clinic _____

Phone Number _____ Phone Number _____

Insurance or MA Number _____ Phone Number _____

Special Needs Information:

Chronic Illnesses/Disabilities/Communication/Equipment/Other _____

See over for medications and other information

B11 *continued*

Medication Information

Medications

Name _____ Dose _____

Name _____ Dose _____

Name _____ Dose _____

Name _____ Dose _____

Name _____ Dose _____

Name _____ Dose _____

Name _____ Dose _____

Name _____ Dose _____

Recent Illnesses/Surgeries/ _____

Living Will? If Yes, Where? _____ No _____

Power of Attorney for Health Care?

If Yes, Who? _____ No _____

Phone number _____

Guardian? If Yes, Who? _____

Phone number _____

Paying For Health Care Fact Sheet

Healthcare is expensive. Teens and young adults need to know how they will meet the cost of their health care as adults. Families need to think about family insurance limits, types of health insurance coverage and ways eligibility is determined. Attention also needs to be given to learning about other possible resources and how to access them. Knowledge of health benefits counseling and advocacy services may also be extremely important. While this fact sheet provides some basic information, it is only a start and each individual situation needs to be explored in a comprehensive and detailed manner.

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Katie Beckett Program

If a young person is receiving Medical Assistance through the Katie Beckett Program and continues to qualify based on disability, that coverage continues until the child's 19th birthday. Parents should receive a letter from the state explaining this before the child's 18th birthday.

Disability Evaluation

If a child has been receiving Medical Assistance through Social Security due to a disability, a new disability determination will have to be made to continue receiving this benefit as an adult. A written notice will be sent around the child's 18th birthday. Continued disability status is not automatic. Similarly, if a young person has not qualified for some programs, like The Katie Beckett Program or even SSI, it may be worthwhile for him or her to apply for coverage through Social Security. There are a number of Social Security programs for people with disabilities. One is the Plan for Achieving Self Support (PASS). This program allows an adult with SSI to exclude some income and assets that would usually be considered. The goal is to help people with disabilities pursue work without losing their healthcare coverage.

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Contact the Department of Health and Family Services at www.dhfs.state.wi.us

B 13

Daily Planner

TIME	ACTIVITY/WHERE/WHO	SPECIAL REMINDERS

Appendix C

Supplementary Background Information for Trainers

Teaching/Learning
Health and Lifestyle
Legal Issues
Web Sites

Teaching/Learning

- American Association on Mental Retardation (AAMR). (2002). *Mental Retardation: Definitions, Classification, and Systems of Supports* 10th Edition. Washington, DC: AAMR.
- Anderson, W. (1997). *The Confidence Course*. New York, NY: Harper Collins Publishers.
- Barclay, J. and Cobb, Jan (2001). *Full Life Ahead: A Workbook and Guide to Adult Life for Students & Families of Students with Disabilities*. Montgomery, AL: Southeast Regional Resource Center.
- Couwenhoven, T. (2001). *Sexuality Education: Building a Foundation for Healthy Attitudes*. Portland, OR: Disability Solutions.
- Disabled and Healthy Project. *Healthy Lifestyles Training Guide: Making Opportunities for Healthy Lifestyles*. Oregon: Oregon Institute on Disability & Development and Child Development and Rehabilitation Center Oregon Health Science University.
- Elder, P. and Goossens, C. (1996) *Communication Overlays for Engineering Training Environments: Overlays for Adolescents and Adults who are Moderately/Severely Developmentally Disabled*, Book IV. Solana Beach, CA: Mayer-Johnson Co.
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Health and Lifestyle

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Lutkenhoff, M., Oppenheimer, S. (Eds). (1997). SPINabilities: A Young Person's Guide to Spina Bifida. Bethesda, MD: Woodbine House, Inc.

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Whitehead, A. ((2000). A Parent's Guide to Home Health Care. Madison, WI: The Wisconsin Council on Developmental Disabilities and the Waisman Center, University of Wisconsin.

Legal Issues

Froemming, R., Abramson, B. (2000). Guardianship of Adults: A Decision-Making Guide for Family Members, Friends and Advocates. Madison, WI: Department of Health and Family Services.

Mather, S., Ed. (2001). Rights and Reality II: An Action Guide to the Rights of People with Disabilities in Wisconsin. Madison, WI: Wisconsin Coalition for Advocacy.

McFarlane, D. (1997). On Being 18. Madison, WI: State Bar of Wisconsin.

Wisconsin Advocacy Agencies for Families and Children with Disabilities

ABC for Health, 152 Johnson Street, Suite 206
Madison, Wisconsin 53703 (608) 261-6939

ARC-Wisconsin, 600 Williamson Street
Madison, Wisconsin 53703 (608) 251-9272

The Internet Public Library
<http://www.ipl.org/ref/>

Coalition for Independent Living Center, 106 Doty St
Madison, Wisconsin 53703
(608) 251-9151

National Family Caregivers Association
<http://www.nfcacares.org/>

Wisconsin Coalition for Advocacy, 16 North Carroll St
Suite 400, Madison, Wisconsin 53703
(608) 267-0214
(800) 928-8778

Rehabilitation Institute of Chicago
<http://www.rehabchicago.org/>

Social Security Administration
<http://www.socialsecurity.gov/>

Wisconsin Council on Developmental Disabilities
600 Williamson Street
P.O. Box 7851
Madison, Wisconsin 53707-7851
(608) 266-7826
(800) 267-3906

State of Wisconsin Information Server, Badger
<http://www.state.wi.us/>

Wisconsin Guardianship Support Center
Elder Law Center
Coalition of Wisconsin Aging Groups
2850 Dairy Drive
Suite 100
Madison Wisconsin
(608) 224-0660
(800) 488-2596

Web Sites

Disability Solutions
<http://www.disabilitysolutions.org>

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

Family Voices
<http://www.ichp.edu/mchb/fv/>

Healthy and Ready to Work National Center
<http://www.hrtw.org>

About the Authors

Debra Gillman brings education and experience, professionally and personally, to the development of this guide. She has been involved in working with individuals with disabilities and their families for more than 30 years.

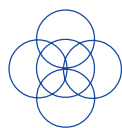
Her involvement began as a teen volunteer. After graduating from the University of Wisconsin-Milwaukee with a degree in journalism, her first job was with the ARC in Milwaukee. Debra did additional graduate studies in Adult Education, and worked at St. Luke's Medical Center in Milwaukee for more than 14 years in the areas of professional development and patient education. She also taught in the Adult Education Program at Milwaukee School of Engineering and in the Weekend College Program at Alverno College.

When Debra's first child was born with a variety of complex special health care needs, she continued to work on disability-related issues as a parent and professional advocate. Since moving to LaCrosse with her family in 1990, she has provided service coordination to families of children with special health care needs in Western Wisconsin through the Gundersen Lutheran Health System. She has also been involved in transition issues through personal experience with her daughter, who is now 20, and her 19-year-old son, who is a college sophomore. Along with her husband of more than 30 years, she continues to be committed to life-long learning and exploring the many transition opportunities life offers.

Ben Schlicht was involved in the conceptualization and development of this Guide, and has co-presented the material as well. He is a 2001 graduate of LaCrosse Central High School. He has many talents and interests. As a young adult with spina bifida and several other related special health care needs, he has personal experience with the transition to adult health care.

Ben has been active in various school and community activities. He won first place in a State forensics competition in high school. He has served on several advisory boards, and given presentations on disability-related issues. He received an A+ Achievers Award from the LaCrosse Tribune, the only student of his high school graduating class to receive that honor.

On the lighter side, Ben is also a graduate of the nationally recognized Clown Camp at the University of Wisconsin-La Crosse and has entertained people with his sense of humor and optimistic outlook on life. He is presently pursuing some of his personal goals - exploring job opportunities and considering independent living options.



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The Waisman Center is dedicated to the advancement of knowledge about human development, developmental disabilities and neurodegenerative diseases. It is one of 9 national centers that encompass both a Mental Retardation/Developmental Disabilities Research Center designated by the National Institute of Child Health and Human Development, and a University Center for Excellence in Developmental Disabilities (UCEDD) designated by the Administration on Developmental Disabilities.

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