

Transition to Adult Health Care



A Training Guide in Three Parts
Second Edition



Wisconsin Community of Practice on Transition
Practice Group on Health

Developed by Debra Gillman in consultation with Ben Schlicht

2009



The Wisconsin Community of Practice on Transition is comprised of a statewide group of key stakeholders who join together to continue to improve collaboration among agency representatives and community partners. The Community on Transition provides a vehicle to share information, bring forth emerging issues and problem solve. Practice groups form around topics of interest, bringing stakeholders together to share their work. The Practice Group on Health recognizes that health is a critical part of every person and must be incorporated into all aspects of transition.



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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 an Intellectual and 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.

To view or download a copy of *Transition to Adult Health Care*, go to <http://www.waisman.wisc.edu/wrc/pub.html>

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A decorative graphic consisting of a large light orange rectangle. Inside this rectangle, there are three smaller squares: a dark orange square in the top left, a green square in the top right, and a teal square in the bottom left.

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The Workbook for Youth



Welcome

If you are reading this, it is probably because you know and care about at least one young person with special health care needs who is preparing for, or is already involved in, transition to adult life.

You may be a parent, sibling or other family member. Perhaps you are a community based professional such as a health care provider, county social worker, teacher, advocate, or someone else who is interested in assisting young people with special health care needs and their families.

You understand that each individual child or youth with special health care needs is unique and each has many of the same hopes and dreams that we all do. Health is an essential component in pursuing those hopes and dreams. For some of us health related issues are more challenging than for others. Whatever we can do to involve young people in understanding their health needs and participating in their own health care will help them pursue of their hopes and dreams.

By virtue of your interest in this training guide you have demonstrated your commitment to helping children and youth with special health care needs learn move toward the promise of their adult lives.

This training guide will explain how to conduct a workshop and options for using the workbook and pocket guide that are included. Care has been taken to emphasize that while we are focusing on preparing youth with special health care needs for adult life, the information and skills presented are important for any young person.

This is just a beginning. Take what works and make it your own. Explore the other resources identified within the training guide. Have some fun. This work is exciting. And thank you for your dedication.

“The Universe has as many
different centers
as there are living
beings in it.”

-Aleksandr I. Solzhenitsyn,
Author and
Human Rights Activist



Who Are Children and Youth With Special Health Care Needs (CYSHCN)?

There are more individuals with special health care need in our communities than ever before. According to the 2005-2006 National Survey of Children with Special Health Care Needs:

- Approximately 10.2 million children ages 0-17 years of age in the United States (13.9%) have special health care needs; and
- 1 in 5 households with children in the United States have a least one child with special health care needs (8.8 million households).

These are remarkable statistics and speak to the advancements in medicine, education and community based services that have evolved over the last fifty years. These statistics also are compelling because they speak to the importance of preparing CYSHCN for adult life.

The federal Maternal and Child Health Bureau defines children with special health care needs as:

Those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.

Any discussion about young people with special health care needs must recognize that this includes an impressive number of individuals along a broad continuum.

Some young people with special health care needs may become fully independent in managing their own health care. Others may continue to need substantial assistance. The hope is that even those who will require considerable on-going assistance will be able to engage in meaningful ways in this important aspect of adult life.

It is important to acknowledge the uniqueness of the transition process for each young person and every individual family. Appreciating and respecting individual differences and preferences is important to all people including those with special health care needs. In addition, transition is a developmental process that cannot be accomplished in a single effort, but must evolve over time.

Health Related Outcomes for CYSHCN

There are many possible goals to work toward as a part of transition. In the area of health and health care, the Maternal and Child Health Bureau identifies six primary areas of focus.

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

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

For example: Jacob has been reading books about seizure disorders from the public library. His parents have helped him select books that are age appropriate and up-to-date. They have engaged him in numerous discussions about his special health care needs over the years and answer his questions as they arise. Jacob has also been included in discussions about treatment options by his parents and doctors expressed in ways that he can understand.

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

For example: Samantha is able to tell people “I have cerebral palsy because I lost oxygen at birth. I use a wheelchair that I am able to operate by controlling a touch pad with my head. I need help with many daily activities such as getting dressed, eating and drinking. I have personal care services through an agency but I can make my own decisions and direct my care.”

3. Monitor their health status on an ongoing basis.

For example: Trevor knows the signs and symptoms for when he needs to use his inhaler for his asthma. He also knows what kinds of situations or activities might trigger an asthma attack and when it is appropriate to use his inhaler as a preventive measure such as before exercising.

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

For example: Marina and her mother have made an appointment for a regular check-up with the pediatrician. Marina is going to ask the pediatrician when she should start seeing a family practice doctor or an internal medicine doctor for her regular care instead of a pediatrician. She will also ask the pediatrician about the differences in how the family practice and internal medicine departments provide care and schedule appointments to see if this should be a consideration in her choice since she sometimes needs to get in to see a doctor for same day care.



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.

For example: Shoua has been getting medical assistance through the Katie Beckett Program based on her disability and she knows that coverage may continue until her 19th birthday. But she is planning to apply for SSI after she turns 18 because she will continue to need medical assistance as her health insurance. Shoua does not have access to her parents' health insurance or private health insurance through her employer since she works only about 15 hours a week because of health related issues.

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.

For example: Javon asks his parents for advice about his medical care because he says they have the longest history with his special health care needs, and he trusts them the most. They are talking about how to make sure he has the help he needs with decision-making after he turns 18 but only in those areas where he really needs it. Javon is also meeting with a benefits counselor at the local independent living center to make sure he knows about programs and options that are available to him in the community.

“Experience is the Name
Everyone gives their
Mistakes.”
-Oscar Wilde

How to Use the Training Guide

How do we prepare our children and youth with special health care needs to meet the challenges of adult health and health care? By using ordinary, every day teaching opportunities and providing lots of practice!

There is no way to provide a specific blueprint or set of recommendations to fit the needs of every individual with special health care needs. The training guide, workbook and pocket guide take the user through a series of activities and exercises. They focus on practical information and skills. The materials have been developed using a collaborative approach, supported by both research and real-life experience.

Regardless of how you plan to use these materials, the starting point is becoming familiar with them and to consider your own perspective on the topics explored. Although this is a comprehensive resource, you may find that you need to do some more study on your own using some of the references provided to feel comfortable working with this subject. After reviewing the content of each of these pieces you will be able to determine how, when, where, and with whom to use them.

The workbook and pocket guide can be used together as:

- **A self-directed study program** for a young person with special health care needs who is capable of reading through the workbook and pocket guide independently and is interested in doing so;
- **A one-on-one teaching tool** with a young person and a learning partner who can provide direction on how to use the workbook and pocket guide; and
- **The foundation for group workshops** for a variety of audiences including teens and/or young adults with special health care needs, parents of children and youth with special health care needs, community based professionals and partners interested in working with CYSHCN and their families.



Tips and Techniques

Whether you are planning on giving the workbook and pocket guide to someone for self-directed learning, using them to coach a young person through a one-on-one learning experience or conducting a group workshop for one of the three target audiences identified in this material, there are some tips and techniques for you to consider as you move ahead. Tips and techniques appear in boxes within the sample script provided for each of the target audiences.

You will notice immediately that all of the materials are organized around a single metaphor: Life is a team sport. This metaphor was chosen to help the learner make a connection to the material by using something familiar.

While not everyone is a sports fan, sports are a common experience that many different people can relate to in every day life. Most people have played a sport in school, as a weekend warrior or as an armchair quarterback. People who have only a passing interest can still listen to a baseball game on the radio, go to a football game or watch a soccer game on television if a team they enjoy rooting for is playing. There is an endless array of sports to choose from involving both male and female athletes as well as a diversity of fans to cheer them on.

Young people with special health care needs may have participated in some kind of sports in high school or may be involved in Special Olympics. This is true for girls as well as boys. There is a reason sports have been around since the beginning of civilization. Using a sports metaphor can build a bridge for learning by making the unfamiliar seem more familiar.

And remember sports are all about teamwork - a life skill important for any one of us. This is especially true when it comes to health care.

“Education is all a matter
of building Bridges.”
-Ralph Ellison

Know Yourself – As a Learner

We all tend to teach in the same style in which we prefer to learn. This is perfectly fine when the individual or group you are working with has your learning style. But that isn't always the case. So be prepared to present the information in ways that accommodate other learning styles. And of course, if you don't already know, you will want to determine your own preferred learning style.

Know your Audience

Principles of adult learning tell us that adults are motivated to learn when they know why they need to know something. They are motivated to learn what they think is important and will make a difference in their lives. They are also more successful if they can use their past experience as a basis for learning new things. These principles work for youth as well.

Learning Styles

There has been an abundance of research about how people learn and various models to identify someone's learning style. Some of these models identify four basic learning styles:

- The first style is a more analytical or fact based approach. These learners are logical and like data as well as understanding how things work. They like to read for information;
- The second style is more interpersonal or social. These learners enjoy discussion and working with partners or in groups. They like to talk through information;
- The third style is creative or imaginative. These learners are usually visually oriented and may draw maps or pictures instead of lists or outlines; and
- The fourth style is more sequential. These learners like step-by-step directions and problem solving. They like things organized and systematic.

Many people have a primary or preferred way of learning but most people can learn effectively in more than one way.

Know the Material

You will want to know and understand the material well so that:

- It feels comfortable;
- It makes sense to you;
- You can focus your attention on the learner(s) not the material; and
- You can adapt it as needed to fit the circumstances in which you are using it.



Setting the Stage

Make sure you select a learning environment that works to enhance learning. If you are working with a group, you will want to have seating arranged to accommodate discussion and physical comfort. You may want to have tables if participants will be writing or if they will be having refreshments. You may want to provide table decorations, music or other creative elements to make the setting more inviting to some learners. Refreshments may be an important consideration. You may want to provide folders with paper for note-taking, pencils and other tangible items. Make sure you have the audiovisual equipment, flip charts or white board and markers and handouts you will need. Pay attention to the temperature of the room.

Engage the Audience

You will want to establish a relaxed and open atmosphere so people will be willing to participate. You will want to make it:

- Friendly by providing introductions and nametags;
- Safe by thanking participants for their contributions;
- Real by asking participants what their concerns are and what they want to achieve by attending the training; and
- Fun by using a little humor.

Evaluate the Results

A sample evaluation has been provided in the appendix. Feel free to adapt it to fit your circumstances.

Timeframe

The modules are presented with a two hour workshop timeframe in mind. Feedback from various presenters identified this as the most effective. The materials can be adapted to fit other time allowances by expanding on certain sections if more time is available and shortening or eliminating discussion of some sections and relying on the learners to do some self study following the actual workshop if there is shorter frame time.

And Finally

Because of the range of potential special health care needs and the unique personalities and characteristics of each individual in each of the target audiences it would be disrespectful, not to mention impossible, to suggest a “one size fits all” approach to this subject matter. Each presenter will have to establish priorities, shift pacing and adapt the materials to fit their circumstances while maintaining the essential themes and structure of the workshops.

Three Workshop Training Modules

In this section you will find narrative outlines for three different workshops, each for a different target audience. If you are an experienced presenter you may want to read through the material and then prepare your own outline. If you are a less experienced presenter you may want to use the material as a basic script. Each of the workshops uses the accompanying workbook and pocket guide as core elements but with a different emphasis depending on the target audience.

Presenters can use the workbook contained in this training guide in several ways. Individual worksheets can be copied as they appear and assembled into a 3 ring binder or a pocket folder with fasteners so the worksheets can be inserted and the pocket guide and/or additional materials can be placed in the pockets. The worksheets from the workbook portion of the training guide can also be copied back to back and used as individual handouts. Based on the needs of the group and the time available for the training, the presenter can determine whether to use all of the handouts or to select only some of them for that particular training session.

Educational research has shown that students remember more if they are in an active, interactive mode while learning. In fact, reading or simply listening to a lecture have the lowest retention rates. Adding audio-visuals improve retention somewhat and watching a demonstration is even better. It isn't until students become a part of the learning that retention improves significantly. This makes a lot of sense.

When we read, listen or see, even in combination, through something like a demonstration or a movie or video, we are still in a passive mode. However, if we participate in a discussion, present ideas or information ourselves, are involved in a demonstration, role play or even a dramatization using a script we are actively learning. Retention goes from as low as 10 to 20% when we read or listen as high as 70 to 90% because now we are saying and doing. Using what we learn immediately and/or teaching what we learn to others are among the most effective ways for us to remember new information or skills.

What does this mean in learning situations? Think of yourself as a facilitator. Even when you present information do so in more of a discussion format. This can be accomplished by pausing and asking questions. Give learners a few minutes to think about the question, engage in a brief discussion with a partner or in a small group and then share some of their responses with the larger audience. Brainstorming is another effective technique that can be used in both small and larger groups. You can also break students into smaller learning groups and have them work together on a task, on case studies or role plays that they then present to the larger group. Use games, especially with youth. Simple matching games like Bingo, competitions based on popular game shows, solving puzzles, or playing pictionary are all examples of familiar games that can be adapted to work with a wide variety of topics.

Module One Script and Tips

A Workshop for Youth with Special Health Care Needs





The workshop for youth focuses on helping the audience realize the value of having a team approach. There is an emphasis on practice through role play that can begin in the workshop but can continue at home. Experience has shown that youth are eager to learn ways to become more involved. While adults frequently say they are uncomfortable with role play situations, young people are much more open to this learning strategy. The training for youth adheres pretty closely to the material in the workbook and pocket guide without some of the more philosophical discussion that may emerge in the other two target audiences.



Welcome to a Workshop for Youth with Special Health Care Needs

Everyone attending this workshop today is getting ready for adult life. For some of you it's just around the corner. For others it may be a while. But either way you all deserve a lot of credit for wanting to prepare for this next big step in your lives.

As an adult you will have more freedoms. And you will have more responsibilities. There will be lots of changes and new experiences ahead. But think about all the changes and experiences you've already been through and the people in your life you feel you can depend on, and you'll realize that you have lots of experience to draw on and lots of people to help you.

In order to make decisions that work well for you it is important for you to understand what will be expected of you after you turn 18 and what you want out of life.

Warm-Up Activity

Let's start by getting to know each other a little better. Let's go around and give your name, your age or grade in school and tell us a little about yourself. Please understand that throughout this workshop we only want you to share what you feel comfortable talking about. You don't have to share something you want to keep private.

Do a round robin of introductions with presenter(s) going first.





Introduce the Worksheets

We're going to use worksheets to help us today. These worksheets are yours to keep. We will go through many of the activities using the worksheets. Whatever we don't get to or anything you want to do more work on later you can do at home. These worksheets may also be a good tool to show your parents or others you like to share information with.

Give Out the Worksheets

The workbook is organized around the idea that **life is a team sport**.

From this point forward, the worksheets and then later, the pocket guide will provide the basis for your presentation and discussion. Hand out the worksheets and direct the participants to the first page. Review the concept of life as a team sport as a practical way for us and our youth to think about this topic.

Review the first page in the workbook. This basically outlines the learning objectives for the workshop.

What's It All About?

It's important to know what will be expected of you as an adult and some of the things you will need to be discussing with your parents and others you rely on for advice. You will want to think about what you really want out of life and what your hopes and dreams are for the future. The area of adult life we are concentrating on today is your health and health care. There are decisions about your everyday life and your health that will affect your future. So let's talk about some of the basic information you need to know about what it means to be an adult.

Now that we know some of the rules let's move on to looking at the how well prepared we may be and where there may also be some opportunities for us to grow.

Using the information in the workbook, review the pages on "What it Means to be an Adult" and "The Rules of 18."

The Health Care Checklist: A Place to Begin

Turn to the Health Care Checklist. Invite everyone to fill it out. Some participants may need some assistance completing this task. Let participants know they can ask for help. You can also suggest they work together in pairs or in small groups. If the checklist seems too big a task to do all at once, you can suggest a limited number of questions to begin with and encourage them to complete the checklist at home. Spend a few minutes talking about the questions and how each person might want to select two or three items to work on.

Who is on your Health Care Team?

Turn to the Everyone Needs a Health Care Team page and do as much as you can to fill in the information. This is another activity that can be completed at home. One point for discussion could be the idea that most people can benefit from having a coach to help them learn the ropes and guide them on their way. Some people have life coaches. Some people have personal trainers to help them with their exercise and diet. It is probably a good idea to have at least one health care coach. Talk about some of the things coaches can do to help- including helping to develop a game plan.

Having a Game Plan and Knowing What to Expect From your Team

Move next to the information in the workbook about Medical Home and introduce this concept. The most important concepts to discuss are the basic components or qualities of Medical Home.

Care Plans

Have you ever been in a situation where your regular doctor is not available and the doctor who is on call asks a million questions about your entire medical history? Have you ever been the Emergency Room and they want a list of the medications you are on, the dose you are taking and how often you take the medication. A handy tool for keeping track of all of this information is a care plan. A care plan is written information that describes a person's health care needs, ongoing interventions and best practice recommendations. You may be able to write your own care plan with help from your parent(s) or with one or more of the health care team members. A written care plan can be helpful in emergencies or when seeing a new doctor. It can also be reviewed in the course of regular



appointments just to make sure everything has been covered and to update the plan to keep it current. Some people put the care plan onto a flash drive so it can be easily carried and available. If you don't have a written care plan ask you parent(s) or doctor about getting one. Keep in mind that your medical information is private and once it is on a flash drive you have to be careful to keep it just for you and your medical providers. Don't use the flash drive for storing other information. Keep it just for medical information and keep it in a safe yet convenient place.

Providing Opportunities for Practice/Giving Honest Helpful Feedback

Move to the worksheets that have the talking points and scripts for:

- How to make an appointment;
- How to arrange transportation for your appointment;
- How to get prescription medications and refills;
- Communication Tips; and
- Preparing for Appointments.

In many ways this is the nuts and bolts section for youth. Hopefully, there will be enough time to do some role play with these tools. If not, select one or two to concentrate on and recommend additional practice outside of the workshop. You may need to demonstrate how to use the tools and do role play.

Bonus Points

Turn to the Healthy Lifestyles Habits section of the workbook. Again review the material, the use of the daily log and how these can be used to provide the youth with a better understanding of health maintenance, identify areas for potential improvements and information to discuss at appointments with health care providers or other members of the health care team.

Health and the IEP are mentioned in the workbook. The best resource for further information is the CD prepared by and available through the Regional Centers for Children with Special Health Care Needs. If possible, incorporate a demonstration of the information within the context of the power point presentation or on its own.

Using the section, "Paying for Health Care" review the information as it is presented.

Give Out the Pocket Guide

The next activity involves sharing the pocket guide and how to use it. Go through page by page. Explain that it would be a useful tool to take along to appointments along with a notebook for writing down information from the appointment.

You will want to do some additional role play using the pocket guide.

Ask for any questions participants have about anything in the workbook or pocket guide. Ask about any questions or concerns about anything that has been covered in the workshop or making the transition to adult health care.

Wrap-up

Remind them that change takes place over time – for all of us – so they should not feel like they have to do it all right away. Repeat the motto:

Start Small. Start Slow. Start Now.

Compliment everyone on the good work they did together. Remind them that they are ahead of the game, so to speak, just by coming today and putting some thought and effort into this topic.

Thank everyone for coming.



Module Two Script and Tips

A Workshop for Parents and Other Family Members





The workshop for parents acknowledges that this is also a time of transition for parents as well as for their son or daughter into adulthood. It also highlights their unique role in providing day-to-day coaching. It is also important to note that some parents of individuals with special health care needs may continue to assume primary responsibility, care management and communication for their son or daughter. Where full or even partial independence is not realistic, parents can be encouraged to use the tools provided to try to bring that young person into the conversation to whatever extent is possible. The workshop for parents also acknowledges that they are the primary gateway for reaching young people with special health care needs. Teachers, health care providers and others may have frequent contact and opportunities with young people, but parents know their child and their history better than any other source. Their engagement in the transition process is essential.

Use the Welcome to a Workshop for Parents and other Family Members and then turn to page 23 and continue with the warm-up activity in Module Three.



Welcome to a Workshop for Parents and Other Family Members

We look forward to spending some time today exploring how we can help families and youth with special health care needs become more involved in their health care and prepare for making the transition to adult health care.

This is a time of change for your son or daughter... and for you as well.

Even though you have known this transition has been coming and you have many years of experience behind you, it may seem as though this moment has appeared quite suddenly, leaving you feeling unprepared. You may feel a little overwhelmed and even a little frightened by what lies ahead.

In this workshop we want to share with you some practical tools and tips so you can resist the urge to panic and enjoy this time of change instead. All we have to do is look around us to remember that we are not alone and that we can use the many skills we have developed over the years and the collective wisdom of others who are also on this journey. One of the first things we can do is to recognize that this is a journey; that transition is a process. This gives us many opportunities.



Module Three Script and Tips

A Workshop for Community Providers and Professionals





The workshop for community providers and professionals invites these individuals to use the workbook and pocket guide in their work with parents and youth. They may find themselves in the position of serving as mentors to both of these groups and may be able to help bridge both shared and divergent concerns that are emerging during the transition years. Community providers and professionals may be working one-on-one with families and may find having the workbook and pocket guide especially valuable as concrete tools they can provide during a time of uncertainty.



Welcome to a Workshop for Community Providers and Professionals

We look forward to spending some time today exploring how we can help young people with special health care needs and their parents prepare for making the transition to adult health care.

This is a time of change for everyone involved – the youth and their parents. Some will experience the shift that occurs as young people assert themselves and become more independent. Many parents may have great apprehension about whether their son or daughter is really up to some of the challenges. This is reasonable since the same thing happens with other youth albeit less intensely perhaps than when there are special health care needs involved.

In some situations, the youth may have significant, complex needs that will limit their independence and even their active participation in managing their own care needs. When parents continue to have primary care-giving and decision-making responsibility for their son or daughter into adulthood, special care must be taken to recognize the challenge this presents for both parent and youth.

Parents may be experiencing a sense of loss at yet one more milestone missed and at the same time, feel guilty for even feeling that way. In addition, as the years progress many of the care-giving tasks become more difficult to do as parents are moving into their middle years or beyond which can present its own challenges. There is also the cumulative effect of years and years of managing situations and systems that can compound stress rather than alleviate it. Sometimes parents are not quite as resilient anymore or are so entrenched in routines that have developed over the years that they cannot break be as creative about possibilities as they might have been earlier on.

Youth with more complex needs may themselves be feeling frustrated by more of the same and may not have a way to recognize these feelings and/or share them with others. They may be experiencing their own disappointment at seeing the independence other people their age or even younger are starting to enjoy that seems out of their reach.

Even though full or even partial independence is not a realistic goal for some, there may still be ways that the young person can be included in or participate in at least some small ways in his or her own care and care decisions.

Some parents may also feel regret about not having done more to prepare for transition. You will want to reassure them that it is never too late to begin. Encourage them to think about any “delay” as an “incubation period” rather than “lost time.” This may help them feel better equipped to move ahead now rather than so overwhelmed that they are overcome with fear and anxiety.

In this workshop we want to share some practical tools and tips that you can use with both youth and their parents. One of the first things we can do is to help them recognize that this is a journey; that transition is a process. It will not happen overnight. But you can be an important travel companion and guide on this journey.



Warm-up Activity

Let's begin by getting to know one another a little better and identify some of our questions and concerns about transition in general and adult health care in particular.

Trainers will want to share some of their own background or experiences related to transition of youth with special health care needs. This helps to establish credibility and build rapport. Learners are more likely to feel comfortable and open to active participation in a safe environment where they have some common ground with the instructor and with one another. The instructor wants to show confidence and expertise without seeming overbearing or arrogant.

Notes

I'll begin. My name is _____ and the reason I am interested in transition to adult health care is _____.

Have group members give their name, a little background and one or two of their questions or concerns about the topic or what they hope to get out of the workshop. Write these concerns on large flip chart paper or on a white board so can go back to them later and make sure each of them has been addressed.

If the group is too large to do this in a time effective manner, you can have people work in small groups, introduce themselves to one another, identify their questions or concerns or what they hope to get out of the workshop and then ask each group to share one or two of them with the larger group. Write these on a large flip chart paper or on a white board for later review.

Identify the Learning Objectives

So, where do we begin? To quote Glinda, the good witch of the west in the Wizard of Oz, “It’s always best to start at the beginning...”

Parents and youth will find it useful to identify some of the key components of the transition process related to health care to determine where they are in relation to them. This gives everyone a place to begin and in a way that let’s them select two or three areas of concentration rather than feeling as if they need to start working on everything at once. We’ll use a checklist to help us look at the information, skills and changing roles involved.

We will explore how using a team approach can help us to set priorities in developing an individualized plan for moving ahead.

We will examine some specific tools to use in involving young people in their own care through every day teaching/learning opportunities. We have a workbook and pocket guide to share with you that you can use with families to help identify some of the skills and information that will help them structure their teaching/learning encounters.

There are six basic outcomes we are hoping to achieve. They have been established by the Maternal and Child Health Bureau specifically for children and youth with special health needs.

Share the outcomes listed earlier in this manual on pages 3 and 4. If you like, you can copy them and give use them as a handout to guide your discussion.



Introduce the Worksheets

As you will see, the worksheets and pocket guide address all of these outcomes in very practical everyday terms and provides specific tools you can use to work on together with parents and/or youth.

The worksheets are organized around the idea that **life is a team sport**.

While not everyone is a sports fan, sports do permeate our culture. Most of us have learned about sports through our own experience or through our children's involvement in them. Most of us participated in sports our own school as an athlete or a fan. Some of us may be "weekend warriors" or "armchair quarterbacks." Sports are a frequent topic of discussion in the workplace.

Even those of us who have only a passing interest can still listen to a baseball game on the radio, go to a football game or watch a soccer game on television if the hometown team is playing. Or we watch the Olympics even though most of the time we couldn't tell you anything about most of the sports that are included. There is an endless array of sports to choose from involving both male and female athletes as well as a diversity of fans to cheer them on.

Young people with special health care needs may have participated in some kind of sports in high school or may be involved in Special Olympics. This is true for girls as well as boys. There is a reason sports have been around since the beginning of civilization.

Remember sports are all about teamwork - a life skill important for any one of us. We don't have to go it alone. This is true for parents and young people with special health care needs. This is especially true when it comes to health care.

Looking at how sports teams work can help parents refocus their roles their teenager's lives. Think about it, as their children get older, most parents spend more and more time on the sidelines...but that's ok because that's where you'll find the coach of any great team – on the sidelines. Every sport relies on coaches. In fact, most sports have an entire coaching staff. For example, in football there's a head coach, an offensive coach and a defensive coach. There's even a quarterback coach. So guess what, you too are a coach – perhaps for both parents and youth!

Activity: How to Be an Effective Coach

Just for fun, let's throw out some ideas about what makes a good coach effective. I'll begin. A coach needs to know the rules and how the game is played.

Write this on a large flip chart page or white board and invite contributions from the group. Be prepared to wait what may seem like an eternity – but is probably more accurately 5 to 10 seconds – for some ideas to start to flow. Write them down. You should hear things like:

- Knowing the rules of the game;
- Assessing the skills of each team member;
- Knowing the roles of each team member;
- Creating a game plan (that includes flexibility);
- Providing opportunities for practice;
- Giving honest feedback in a helpful way; and
- Having a playbook to help keep things organized.

Or you can omit this activity and simply identify the seven bullet points identified. It has been used with a variety of workshop audiences and has been at getting people to participate.



Give Out the Worksheets

From this point forward, the workbook and then later, the pocket guide will provide the basis for your presentation and discussion. Hand out the workbook and direct the participants to the first page. Review the concept of life as a team sport as a practical way for us and our youth to think about this topic.

Some presenters may feel uncomfortable using the sports metaphor. If you simply cannot get past this idea, even after you have tried it a few times, you can substitute another metaphor with which you are more comfortable. Think about all of the areas in life where coaches are involved. This ranges from debate teams to voice coaching for singers. Realize as well that a coach is basically a mentor or team leader. There are lots of different venues in which mentors or team leaders are found.

Knowing How the Game is Played

Let's begin by considering what it means to be an adult. This is something that we don't often talk about with youth.

Use the information on the pages "What it means to be an adult." and "Some of the 'Rules' of 18". In sharing and discussing this information attention needs to be given to the legal definitions of competence, the presumption that someone is competent upon reaching age 18 regardless of degree of disability unless otherwise determined through a legal process and the various options available beyond full guardianship.

Now that we know some of the rules let's move on to looking at the how well prepared the youth or young adult may be and where there may be some opportunities for growth – for them and for us.

The Health Care Checklist: A Skills Assessment

Ask participants to turn to the Healthcare checklist in the workbook. Ask them to complete the checklist from their perspective. You can encourage participants to spend a few minutes talking with a partner about how they filled it out and how they think some of the parents and/or youth they work with would answer these same questions..

Who's On First?

Let's look at who is part of the health care team, what they bring to the team and who else might make valuable contributions to the team as things are changing in the transition to adult health care.

Turn to the Everyone Needs a Health Care Team page to take a quick look at who is on the health care team and whether there need to be any additions or substitutions.

Having a Game Plan

Using the Medical Home concept is part of the game plan as outlined in the workbook. You may want to provide some additional materials describing Medical Home. This is a good point at which to talk about the Regional Centers for Children and Youth with Special Health Care Needs in Wisconsin and the information available through their websites. Also point out the websites listed on the handout and encourage participants to visit them for more in-depth information and a variety of resources.



Providing Opportunities for Practice/Giving Honest Helpful Feedback

Move to the worksheets that have the talking points and scripts for:

- How to make an appointment;
- How to arrange transportation for your appointment;
- How to get prescription medications and refills;
- Communication Tips; and
- Preparing for Appointments.

Do a very quick review stressing how to use these tools and whether or not to use them depends on individual needs, preferences and abilities.

Bonus Points

Turn to the Healthy Lifestyles Habits section of the workbook. Again review the material, the use of the daily log and how these can be used to provide the youth with a better understanding of health maintenance, identify areas for potential improvements and information to discuss at appointments with health care providers or other members of the health care team.

Using the section, “Paying for Health Care” review the information as it is presented.

Health and the IEP are mentioned in the workbook. The best resource for further information is the CD prepared by and available through the Regional Centers for Children with Special Health Care Needs. If possible, incorporate a demonstration of the information within the context of the power point presentation or on its own.

Developing a Health Notebook

The worksheets are a starting point for developing a system for maintaining health related information. This is a long term project but one that can begin with a notebook, a three-ring binder or accordion style file folder. Some people may prefer to do this electronically or with a flash drive. You may be able to provide some kind of organizer or notebook to help get this project going. Ultimately, it can include background information and a health history but also can help keep track of information from medical appointments and other information and planning tools for future consideration. Let's look at some examples and possibilities that might work well. This can be encouraged as an activity for parents and youth to work on together.

There are several examples and resources included in the appendix of this training manual that can be shared as handouts.

Care Plans

A Care plan is something that could be developed as a part of any health related file or notebook. A care plan is written information that describes a person's health care needs, ongoing interventions and best practice recommendations. Some parents and/or youth may be able to write their own care plan or may develop one with one or more of the health care team members. A written care plan can be helpful in emergencies or when seeing a new doctor. It can also be reviewed in the course of regular appointments with established members of the health care team to make sure all areas have been covered and to update the plan as needed to keep it current. Some people put the care plan onto a flash drive so it can be easily carried and readily available. It can stay in a child's backpack so it is always available in case of an emergency.



Give Out the Pocket Guide

The next activity involves sharing the pocket guide and how to use it. Go through page by page. Explain that it would be a useful tool to take along to appointments along with a notebook for writing own information from the appointment. Be prepared to offer suggestions for how to make adaptations based on individual needs, preferences and abilities. Solicit ideas from participants on how they think this tool might be useful to them in working with parents and youth with special health care needs.

Return to the questions or concerns identified at the beginning of the workshop. Review each of them and how they have been addressed. If there are any unmet needs bring them forward for discussion and provide a reference or resource for follow-up.

Revisit the Health Care Checklist

Let's take another look at the health care checklist you filled out earlier. This is where you will encourage families to begin making their plan. Encourage them to select two or three items to work on. Talking about the checklist may help families see which of the items on the checklist each might be most interested in.

Again, you may need to be that voice that reminds parents and youth not to worry about how much there is to do... not to worry about whether you should have started sooner... or about making mistakes or not getting it right. No matter how good they are, no team wins every game. And success takes practice.

Just as you will tell families, don't wait for the perfect team, or the perfect time or to be the perfect coach.

Start Small. Start Slow. Start Now.

And good luck.

Appendices





Additional Resources

Related Materials

Health and the IEP is a comprehensive tool for understanding how to incorporate health into the IEP developed by the Children and Youth with Special Health Care Needs Regional Centers and the Waisman Center. It is available as a CD-ROM and on-line at www.waisman.wisc.edu/cshcn/publications.php

For information on **Medical Home** go to www.wimedicalhometoolkit.aap.org and www.medicalhomeinfo.org/about/index/html

Transition to Health Care Checklist: Preparing for Life as an Adult is a resource to help youth and young adults with special health care needs make a successful transition to adult living that includes their education, health and community living. This checklist contains a wealth of information and resources. The checklist can be downloaded from www.waisman.wisc.edu/cshcn/publications.php

University of Wisconsin Pediatric Pulmonary Center has a series of booklets for youth to help them prepare for the transition from **pediatric specialty care to adult specialty care** services at <http://www.uwppc.org/resources>

National Resources

The Maine Support Network is a professional development resource for educators. It offers handouts and articles on teaching approaches and strategies including **celebratory learning** at www.mainesupportnetwork.org/handouts/htm

Sample Care Plans are available through: the Healthy and Ready to Work National Center www.hrtw.org; the American Academy of Pediatrics at the National Center of Medical Home Initiatives for Children with Special Needs www.medicalhomeinfo.org/tools/assess.html; and the Wisconsin Pediatric Pulmonary Center <http://www.uwppc.org/resources>

State Resources

The **Wisconsin Guardianship Support Center** (Coalition of Wisconsin Aging Groups) provides information on guardianships, protective placements, conservatorships, Powers of Attorney for Health Care, Living Wills, Do Not Resuscitate Orders and Powers of Attorney for Finances. Call 1-800-488-2596 extension 314 or on-line at <http://cwag.org/legal/guardian-support>

The **Wisconsin Department of Health Services** website has disability and benefits information to Wisconsin residents <http://dhs.wisconsin.gov/ddb/index.htm>
Wisconsin's five **Regional Centers for Children and Youth with Special Health Care Needs** provide information and assistance to families and providers <http://dhs.wisconsin.gov/health/children>

Sample Evaluation Tool

List two new things you learned about how to be more involved in making the transition to adult health care

1.

2.

What will you do differently as a result of what you have learned?

Will you share this information with someone? If so, who?

How can we improve the information that was presented to you?



Emergency Medical Information Card



Name _____ Date of Birth _____

Address _____

Allergies to Latex or Medications: _____

Phone () _____

Emergency Contacts:

Name _____ Relationship _____

Phone () _____ Primary Doctor _____

Healthcare Contacts:

Doctor _____ Phone () _____

Hospital/Clinic _____ Phone () _____

Insurance Card Number _____ Phone () _____

Special Needs Information:

Chronic Illnesses/Diagnosis/Disabilities/Communication/Equipment/Other _____

Other Important Stuff _____

How I Communicate _____

Turn over for medications and other information

Emergency Medical Information Card



Name _____ Date of Birth _____

Address _____

Allergies to Latex or Medications: _____

Phone () _____

Emergency Contacts:

Name _____ Relationship _____

Phone () _____ Primary Doctor _____

Healthcare Contacts:

Doctor _____ Phone () _____

Hospital/Clinic _____ Phone () _____

Insurance Card Number _____ Phone () _____

Special Needs Information:

Chronic Illnesses/Diagnosis/Disabilities/Communication/Equipment/Other _____

Other Important Stuff _____

How I Communicate _____

Turn over for medications and other information

Emergency Medical Information Card

Medications:

Name _____	Dose _____
Name _____	Dose _____
Name _____	Dose _____
Name _____	Dose _____
Name _____	Dose _____
Name _____	Dose _____
Name _____	Dose _____
Name _____	Dose _____
Name _____	Dose _____
Name _____	Dose _____
Name _____	Dose _____

Power of Attorney for Health Care? Yes _____ No _____

If Yes, Who? _____

Phone () _____

Additional Information _____

Emergency Medical Information Card

Medications:

Name _____	Dose _____
Name _____	Dose _____
Name _____	Dose _____
Name _____	Dose _____
Name _____	Dose _____
Name _____	Dose _____
Name _____	Dose _____
Name _____	Dose _____
Name _____	Dose _____
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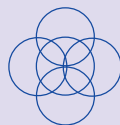
Power of Attorney for Health Care? Yes _____ No _____

If Yes, Who? _____

Phone () _____

Additional Information _____





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