

Transition Health Care Checklist: Preparing for Life as an Adult



A resource to help youth and young adults with special health care needs and disabilities make a successful transition to adult living that includes their education, health and community living.



Wisconsin Community of Practice on Transition
Practice Group on Health



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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, at the University of Wisconsin-Madison, 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, download or order a copy of *Transition Health Care Checklist: Preparing for Life as an Adult* go to <http://www.waisman.wisc.edu/cedd/pdfs/products/health/THCL.pdf>

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A decorative graphic consisting of a light orange background with three colored squares: a dark orange square, a green square, and a teal square.

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About This Booklet

Overall Purpose

The *Transition to Health Care Checklist* booklet is intended for youth and young adults who are preparing for the transition to life as an adult. The purpose of the booklet is to provide a general overview of the knowledge, skills and actions that need to be addressed as part of the fluid process of adolescent transition for youth with special health care needs.

For Youth and Young Adults

Congratulations—by opening this booklet, you have taken the first step in a multi-step process that will help you face some important changes as you move toward living as an adult. That move from youth to adulthood is called transition. This booklet is meant to help you with transition planning in Wisconsin.

Transition planning is about future education and work plans, living arrangements, and finances. It is about how to manage a health care condition or disability as independently as possible. You will learn a lot about all these topics in this booklet. Because there are many parts of transition planning, you and the people who help you with transition planning may use several resources like this one. You may use some other resources that focus on such issues as employment, self advocacy, and community services and supports. And at any one time you may only need to use part of the booklet or part of the Skills Checklist. Just use the parts that you need at any given time.

This booklet is meant to help you identify the skills you will need for independent adult living. You can use the Skills Checklist in the middle of this booklet to identify some of those skills. Other parts of this booklet are meant to help you get familiar with issues related to transition. This booklet is designed for you, your family, and the school, health care, and other staff who may be helping you. Everyone who helps you with transition planning is part of your transition team. This booklet is designed to help you and your transition team from the start of transition planning through your completion of high school.

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Preparing for Transition

Transition is a time for learning new information, developing new skills, making decisions and taking action. All of this involves some important planning. This section is about some of the basic things you need to do to prepare for transition, and how this booklet can help you.

What do I need to do?

Understand Transition

You will need to learn about the services, benefits and options available to adults.

Develop Skills

You will need to develop some skills to be as independent as possible.

Make Decisions and Take Action

You will need to look at the choices you have and make some decisions based on what you want and need.

How can this booklet help me?

Look through the Timeline and Fact Sheets. This information will probably raise many questions for you and you can ask for help from the people who support you.

The Transition Checklist for Teens can help you identify skills related to health care needs and other issues that you want to address. Once identified, work with your team to find ways to develop these skills.

Information on making transition plans will help you to decide how to document your decisions and the actions that you need to take to make a decision a reality.

Get More Help...

A **Glossary of Abbreviations/Acronyms** begins on page 47 and spells out the frequently used terminology. Important abbreviations/acronyms and transition terms will be in **bold**.





Understanding the Transition Timeline

Each transition is different. The timeline below is a guide and may be useful to you as you consider your own needs, interests and preferences.

Early Transition Skills: Ages 13-14
<ul style="list-style-type: none"> • Start taking responsibility for your health care needs, such as making your own appointments or meeting with your health care provider alone for at least part of your appointment. • Be a part of the IEP team and remember that transition services are part of the IEP.
Middle Transition Skills: Ages 15-17
<ul style="list-style-type: none"> • Start thinking about how and when you will transition from pediatric to adult health care. • Gain work experience through volunteering, job shadowing, and part-time employment. • Ask school staff about a referral to the Division of Vocational Rehabilitation (DVR). • 15 years: Investigate driver education options if you wish to obtain a driver's license at age 16. Consider what accommodations you might need. • Explore futures planning tools. • Learn more about services that are available to you as a young adult, including adult long-term care, and where and when to apply. • 17 years 6 months: Get screened for long-term care eligibility at the ADRC. • Think about how you will make big decisions because when you turn 18, you will have the right to make all your own decisions about health care. You may want to have someone else help you make decisions. • Prepare documents related to power of attorney for health care, power of financial attorney, medical directives and/or guardianship if needed. • 17 years 6 months: Get updated medical and psychological evaluations if your family plans on going through guardianship processes. • 17 years 9 months: Your parents may apply for guardianship.
Late Transition Skills: Age 18 and beyond
<ul style="list-style-type: none"> • 18 years: Power of health care attorney, power of financial attorney, medical directives and/or guardianship, are in place if needed. • 18 years: Apply for SSI and Medicaid as an adult if eligible. • Take increased responsibility for managing health insurance coverage. • Make decisions about future plans for work, school, and where you will live. • Enroll in an adult long-term care program if eligible. • Register for Selective Service if you are a male. • Register to vote. • 21 years: Complete the transition to adult health care providers, unless special provisions are made. • 21 years: Finish public school; special education services end at age 21. The school must provide a summary of your performance to help you meet your post-secondary goals. • 26 years: Stay on your parent's health insurance plan up until age 26, if needed.



Developing Skills for the Future

Transition is about preparing for life as an adult which may include:

- caring for your own health and medical needs
- attending a university or community college
- getting job training
- getting a job
- living away from home
- getting around in the community
- engaging in individually meaningful activities

What skills do you have now?

What skills will you need?

How are you going to develop the skills you need?

Transition begins by the time you are 14 years old

Many important changes in services and legal status occur between the ages of 18 and 21. But planning for transition may begin before you turn 14 years old, and may continue beyond when you turn 21 years old. For many young adults, much of the transition planning happens between 14 to 21 years of age.

Transition is about developing needed skills

All young adults need to develop skills to support adult life and independent living. To help prepare for life as an adult, you can think about what skills you need to develop. As you develop the skills keep thinking about what skills you want to work on next. You can use the Transition Checklist for Teens to identify which skills you have now in health care and other areas, and which skills you can work on developing. Share the result with your **Individualized Education Program (IEP)** team to consider as IEP goals.

Learning about the parts of transition

There are many pieces to the transition process, so it may be helpful to think about transition in three parts: health care, education, and community living. You can learn more about these parts of transition on the following pages. You can use the *Fact Sheets for Making it All Happen* section to learn more about specific topics that may be important for your transition planning. For example, you can learn more about work, insurance and paying for services, financial and legal issues, and assistive technology. You can also create your own transition plan, using the Department of Public Instruction's Postsecondary Transition Plan at: dpi.wi.gov/sped/about/state-performance-plan/indicators/13-transition

Get More Help...

In this booklet, you'll find "**Get More Help...**" shaded boxes like this one telling you about more resources that might be helpful to you.

You'll find other important resources listed in the section called "**Additional Resources.**"





Transition Planning: Make Decisions and Take Action

Transition planning starts with you

A transition planning process includes the steps you take to move into the adult world. There is new information that you will need to learn about, independent living skills to develop, decisions to be made and actions to take. You are the most important person in planning your own transition. But you don't have to do it alone. Others can help you by providing information, meeting with you to listen to your hopes and dreams for your future and by assisting you to develop a transition plan.

There is no one way to make a plan. Many people find that writing down a plan is helpful. This can keep everyone informed and focused. There may even be more than one written plan. For example, you may have a written transition plan with your primary health care team or other health care provider, school plan such as the Individualized Education Program (**IEP**), and a written plan such as a county-based program's individualized service plan.

The next section of this booklet is all about how to get started with transition planning. You'll learn about a few important places where transition planning will happen, who can help you, and how to work well with everyone on your team.

Get More Help...

WI First Step is a public health information and referral hotline for children and youth ages birth to 21 with special needs, serving families and professionals. To learn more call **800-642-7837** or go to:
<http://www.mch-hotlines.org>

WI Regional Centers for Children and Youth with Special Health Care Needs (CYSHCN) staff answer questions, provide information and referrals, and provide free and confidential assistance to youth with special health care needs and their families and providers. To find out which of the five Regional Centers serves your county go to:
<http://www.dhs.wisconsin.gov/cyshcn/regionalcenters.htm>

Got Transition? is a national center that has a focus on the transition from pediatrics to adult health care. To learn more go to:
<http://www.gottransition.org/>

Opening Doors to Self Determination Skills is a Department of Public Instruction booklet with great resources around self determination. To learn more go to:
<https://pubsales.dpi.wi.gov/product/opening-doors-to-self-determination-skills/>

Transition Improvement Grant (TIG) within the Department of Public Instruction, provides professional development to Wisconsin youth, parents, educators and all stakeholders in the area of postsecondary transition. To learn more go to:
<http://www.witig.org/>



Getting Started with Transition Planning

Now that you know a little bit about what transition planning is all about, you need to know how to get started! Transition planning is a process that evolves over time. As you go through this process, you will try things out and make decisions about what works best for you. So don't worry about making just one transition plan that does it all. It's a work in progress, and it can change as you continue to explore new possibilities and make choices that work for you. As you grow and change, your transition plan should grow and change.





Transition Teams

Transition planning is a team effort

You are the most important person in planning your own transition. What you need and what you would like for your future are the highest priority. But while you are the lead in your transition, many young adults benefit from having others to help with this process. Anyone who works with you and your family can help you to develop specific transition plans. It might be helpful to think of you and these other helpers as your own transition team. You might include people on your team like your family, friends, primary and specialty health care providers, teachers, principals, school administrators, school and community therapists, school nurses, social workers, Division of Vocational Rehabilitation (DVR) counselors, mental health providers, county-based program providers, and anyone else you choose to include.

Everyone who helps you with transition planning is part of your team

Having a transition team makes the process easier.

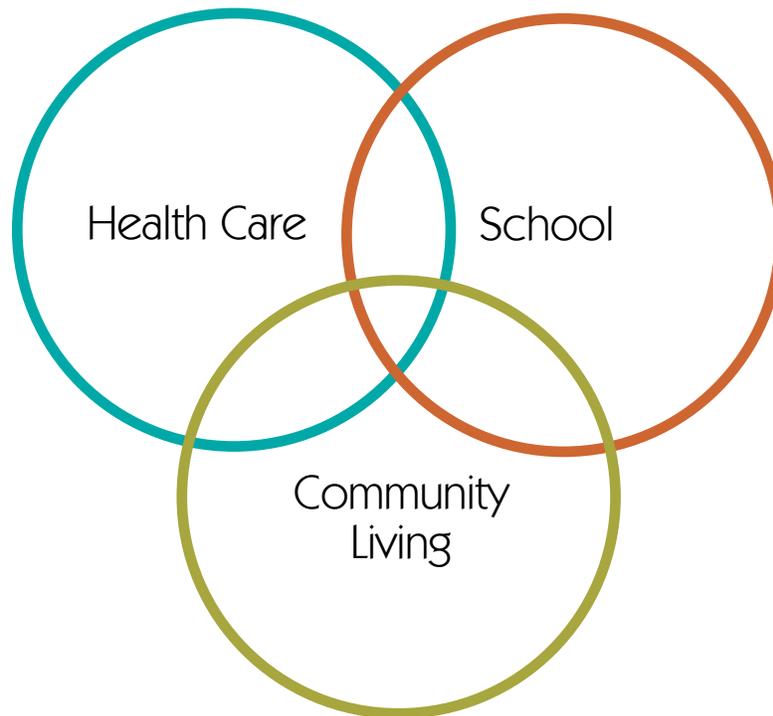
- The purpose of the **transition team** is to support you to make the transition to adult living and be as independent as possible.
- The **transition team** includes everyone who helps with transition planning and services.

The big transition team is made up of some smaller teams

Transition planning actually happens in more than one place. So it may feel like there are actually several transition teams! This is because you will do transition planning in health care, education, and in the broader community. It may be helpful to think about the people who help you with each part of your transition as a smaller team. There may be a **health care team**, an **Individualized Education Program (IEP) team**, and a **community living team**. Each team has a specific purpose. Sometimes different people are on these teams. For example, your primary care physician is an important member of your **health care team**, but may not participate in your **IEP** meetings. Sometimes the same people are on more than one team.



Your Transition Team



- The purpose of the **health care team** is to plan and support your transition from pediatric to adult health care. You can work with your health care team and school team to make sure your health and medical goals are reflected in your **IEP**.

The **health care team** includes you and your family, primary care provider, specialty care, medical care staff, and other health care providers.

- The purpose of the **school team** is to develop and implement an **IEP**. The **school team** will work on the transition plan to be included in your **IEP**.

The **school team** includes you and everyone who is formally involved in developing your **IEP**. At a minimum, it must include: you, one of your parents or your primary caregiver, a regular education teacher, a special education teacher, and a **Local Education Agent (LEA)** (a school district representative).

- The purpose of the **community living team** is to help you plan and support your transition to adult living, including your job and the informal supports and community-based services.

The **community living team** includes everyone involved in helping you plan and live within your community, including county-based program staff.





Transition Planning in Health Care

The health care transition process

Every young person is growing, gaining responsibilities and moving toward becoming an adult. Adults have different health care needs than children. As a young adult, you can consider how you want to transition from pediatric to adult care or begin to work more independently with your family medicine physician.

In preparation for adult life, young adults with a variety of conditions or disabilities must consider how to manage their own health care needs. Everyone needs to know when to seek medical care and when to take medication. It is important for you to understand your health condition or disability. It is also important for you to understand health risks, how to make healthy life choices, and how to exercise independence in health-related issues.

Integrate goals into your IEP

Health-related goals can and should be included in your Individualized Education Program (IEP). The Transition Checklist for Teens on page 14 lists health care and other issues that might need to be addressed as part of the transition plan. It can be used to help develop goals to be included in your IEP.

Seek coordinated care

Primary care providers are those doctors/physician assistants/nurse practitioners who provide general medical care to meet most of your health needs. When you have a regular provider that you go to for routine care, then you have what is called a Medical Home. Your pediatric primary care provider should help you when it is time to transition from pediatrics into adult health care. He/she should make sure you can get the health-related services you need at home and in the community.

Include specialists and others

You may have a strong relationship with pediatric medical specialists. It is important to have them help you transition to adult specialists, since many patients stop getting care from pediatric specialists by the time they are between 18 to 21 years old. If personal care workers, nurses and/or therapists help you at home, you will want to ask about whether these services will change or end when you become an adult.

Get More Help...

Medical Home is an approach to assure that you have one primary care provider to coordinate your health care needs. To learn more go to:
<http://www.medicalhomeinfo.org/>

An **Emergency Information Form** is available online. To learn more go to: www.aap.org/en-us/about-the-aap/Committees-Councils-Sections/section-hematology-oncology/Documents/emergency_info_form.pdf

Health Transition Wisconsin is a website with transition resources for teens, families, and providers. To learn more go to:
<http://www.healthtransitionwi.org>



Health Care Communication Basics

People sometimes say that communication is a two-way street. But when it comes to communication and health-related issues for young adults, it is usually a three-way street:

parent(s) + school staff or health care provider + young adults

Transition is a time of changing roles and expectations. It is a time for you to actively assume more responsibility. It is also a time for parents and health care providers to encourage this change to the greatest extent possible, even when youth have special health care needs. Open communication is essential to this process so the three-way street becomes:

young adults + school staff or health care provider + parent(s) as needed

Key Questions for Young Adults, School or Health Care Provider and Parents

- Do I show others the respect I want to receive?
- Do I listen carefully and completely to questions or comments before responding?
- Do I participate in discussions willingly and with an open mind?
- Do I accept responsibility for my actions and opinions?
- Do I ask for further explanation when I don't understand something?
- Do I actively participate in planning and problem solving?

Key Questions for Young Adults

- Do I participate in my appointments by offering information, answering questions, expressing my concerns and asking questions?
- Do I express my own thoughts and feelings even when they differ from my parent(s) or school/health care providers?
- Do I ask for some time alone with my school nurse or health care provider at my appointments for private discussion, and am I able to ask questions without feeling embarrassed?

Key Questions for Providers

- Do I focus my attention primarily on the youth rather than the parent?
- Do I discuss topics that are age and developmentally appropriate and include but are not limited to the youth's special health care needs?
- Do I offer the youth time alone for private discussion?
- Do I respect confidentiality as much as possible?
- Do I create a comfortable environment that encourages collaboration?

Key Questions for Parents

- Do I actively encourage my son or daughter to participate as fully as possible?
- Do I actively encourage the school and health care provider to do the same?
- Do I facilitate confidential communication between my son or daughter and his or her providers to the greatest extent possible?
- Do I recognize my own legitimate needs as a parent during the transition process and seek appropriate supports and resources to meet these needs?





Transition Planning in Education

IDEA 2004

Federal regulations require transition planning to be included in the **IEP** the year a student turns 16.

In Wisconsin

When a student reaches the age of 14, the **IEP team** must formally begin planning for the student's transition to life beyond high school.

It begins when you are 14 years old

In Wisconsin, postsecondary goals based on age-appropriate transition assessment are required to be part of your **Individualized Education Program (IEP)** no later than in the year you reach 14 years old, and updated annually. This is known as a postsecondary transition plan. However, the earlier you and all members of your overall transition team and your IEP team begin to think about what you will need or do after high school, the better prepared everyone will be to make the plans become a reality.

It ends by the time you are 21 years old

Once you graduate from high school or reach the age of 21, help is no longer available from the public schools, though, if you turn 21 during a school year and have

not graduated, you may finish out the school year. To avoid gaps in services, you must have adult services in place before graduation or before the school year in which you turn 21. Be sure to ask for a Summary of Performance before leaving school.

Include all relevant people

As part of the planning process, your **IEP team** must invite any outside agencies that are likely to provide or pay for transition services to participate. This may include representatives from agencies such as **DVR**, the county human services agency, or **SSA**. It is important to have community agencies involved in the process as early as possible so they can help with the necessary planning and preparation.

Relevant, meaningful experiences

Transition planning continues throughout high school with instruction, job exploration and community experiences to support your post-high school outcomes. Planning will include choosing a course of study that provides the experiences needed for you to be successful as an adult. The course of study should also be meaningful and motivating to you.

Get More Help...

Transition Action Guide for Post-School Planning is a resource on transition planning. To learn more go to: http://dwd.wisconsin.gov/dvr/pdf_files/tag.pdf

WI FACETS provides training, information, referrals, and individual assistance related to special education and IEPs. To learn more call **877-374-4677** or go to: <http://www.wifacets.org>

Transition Improvement Grant (TIG) and the **Community of Practice on Transition** has partnerships to support students and their families around transition. To learn more go to: <http://www.witig.org/>

Transition Through High School Guide Provides information on different activities that are part of the transition process. To learn more go to: <http://www.witig.org/Transition Through High School Guide.pdf>



Transition Planning for Community Living

Transition means change

You may choose to live with your family into adulthood, or you may want to experience independent living. Maybe you will go back and forth between living with your family and living independently. But no matter which choice you make, most community-based resources and services change with the move from childhood services to adult services. The Family Support Program, for example, does not continue into adulthood. Other resources like how to get supported at the work place, will be new to you. It's important to plan for the transition from the childhood service system to adult services. Your community living team is made up of the people who help you plan this transition.

Skills for community living

Regardless of where you live as an adult, you will need to develop skills to be as independent as possible in your daily life as an adult in a community. Some important skills for adult living include knowing how to make decisions, making time for friends and family, advocating for yourself, managing activities of daily living, being safe, maintaining a healthy lifestyle, accessing transportation, engaging in recreational activities, and making sure you have health insurance coverage.

Include all relevant people

Support for community-based living comes from agencies as well as informal supports. The community living team may include you, your family, county program service providers, informal supports (friends, faith community, and neighbors), and anyone else who supports you in community-based living. This team will most likely overlap with the health care and school teams. The community living team may engage in a "PATH Futures Planning" or similar process to explore the possibilities for adult life. If you want to learn more about PATH Futures Planning, check out the information at the bottom of this page.

Get current county information

Much of the funding for **Medicaid** and human services is administered at the county level. This means there is a lot of variation in how community-based services are structured in counties across Wisconsin. The state has an adult long-term care system which has options available based on eligibility, county of residence, and some consumer choice. Because there are regular changes to services and insurance coverage plans, it is very important to check with the appropriate state, county, or other agencies for up-to-date information on programs available in your area, and whether you are eligible for them.

Get More Help...

PATH Futures Planning is a creative team approach to planning for adulthood. To learn more go to: <http://www.inclusion.com/path.html>

Wisconsin Independent Living Centers are consumer-directed, non-profit organizations that provide four core services: peer support, information and referral, independent living skills training, and person and systems advocacy. To learn more go to: <http://www.dhs.wisconsin.gov/disabilities/physical/ilcs.htm>





Identifying Skills for Independence

An important part of planning your transition to living in the community as an adult is figuring out what skills you will need and how you are going to develop them.

This next section focuses on helping you identify the skills you will need for independence. It includes a list of skills related to health care and other areas that is set up as a checklist. You and your transition team can go through the Transition Checklist for Teens and add a check mark to each skill you have now. Then you can work with your transition team to decide which skills you need to develop, and how you will do that. Don't forget to work with your health care, school and community teams to figure out how working on these skills can be written into your transition plans.

This checklist includes some of the skills you will need for independence as an adult. But you and your transition team will probably think of other skills that aren't included here! You can add your own skills to the end of the list. Once you figure out what skills you need to develop, it will take time to develop them. Each year you will may be able to check off more skills from this checklist.

If you think you might want to fill out a clean copy next year, make copies of the checklist now, before you fill it out.





Transition Checklist for Teens

This **Transition Checklist for Teens** is about the skills you need to learn to take care of your health when you become an adult. Your doctor or nurse will talk with you about the areas where you want help. Please complete this checklist by marking the box or boxes that describe you the best. If you do not understand a question, please ask your parent, nurse, or doctor for help.

Early Transition Skills: Age 13-14	YES, I do	NO, I will learn	Someone will need to do this for me	N/A, Will not be needed	Need more info
Do you wear or carry a medical alert (list of allergies, conditions)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you speak up for yourself in your doctor's office?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you help make health care decisions with your family or doctor?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you see your doctor without your family/parents in the room?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you know how to describe your own health conditions/disabilities and do you know how they affect your daily life?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you know how to maintain a healthy lifestyle (diet, activity, etc.)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you understand how smoking, drinking, and/or using drugs can affect your condition (worsen symptoms, react with your medicines)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Middle Transition Skills: Age 15-17					
Do you know your rights to keep your health information private?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you call your doctor(s) on your own if you have a problem?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you know how to schedule your own doctor appointments?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you know the names of your medicines and why you take them?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you know what can happen if you skip your treatments or medicine?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you know how your condition affects sexuality (the need for closeness, caring, and touch, sometimes involving sexual activity)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you know what you'll do for birth control, safe sex, and reproductive concerns (genetics, pregnancy)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you know how to use your health insurance benefits (co-pays, referrals)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you know what you will do after high school (job, more school, recreational options, volunteer, etc.)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you know of resources that can help you to find adult services (job support, transportation, assistive technology, etc.)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you know how your condition might affect your job choices?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Late Transition: Age 18 and beyond					
Do you have an updated portable medical summary and/or care plan?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you have an adult doctor (or a doctor for while you are at college)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you almost always take your medicines correctly on your own?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you know when and how to fill your own prescriptions (knowing who prescribed and where to call, getting refills on time)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you use and take care of your own medical equipment and supplies?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you know when to call for routine checkups, urgent care, and when to go to the emergency room or call 9-1-1?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you know who to call for questions about your insurance coverage?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you know how you will maintain health insurance as an adult?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you know what government benefits you might qualify for (SSI, SSDI, Health Benefits for Workers with Disabilities, Home & Community Based Services, etc.)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you know about guardianship or power of attorney for health care?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you know your options for housing as an adult (on your own, group home)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you know how to manage your money and pay your bills?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Adapted with permission from the American Academy of Pediatrics-Illinois Chapter, *Transition Checklist for Teens*, <http://illinoisaap.org/projects/medical-home/transition/resources-for-physicians/>.

Materials supported through a grant from the U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau, D70MC12840. Developed by the UIC - Division of Specialized Care for Children and the Illinois Chapter, American Academy of Pediatrics.



Fact Sheets for Making it All Happen

You may still have a lot of questions about transition planning. This next section of the booklet includes some important fact sheets about:

A. Financial and Legal Concerns	16
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D. Work and Disability Benefits.....	26
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Some of this information was pulled directly from agency websites or publications. The source of the information is always listed under the Fact Sheet heading. For more information there are website links in the “get help” boxes.

This section contains a lot of detailed technical information. Information like this is often very complicated and it also changes regularly. So it is really important to check with the agency listed for the most accurate and recent information. In the meantime, this section is meant to introduce you and your transition team to some of the issues that may be important to you during your transition planning.





A. Financial and Legal Concerns

The following financial and legal information was developed by Roy Froemming, private practice attorney, Madison, Wisconsin.

Meeting needs for decision-making support related to finances, property and self-support

Identify major concerns related to finances, property and self-support:

- Is there a need to protect the young adult's financial resources to ensure payment of bills for basic support?
- Is there a need to ensure that larger resources are protected from loss (e.g. a home, a future inheritance, significant savings or retirement benefits) through poor management, bad decisions or exploitation by others?
- Can the person give a legally valid consent to needed contracts, such as leases?

Consider the following tools and options:

Informal advice and support. Person has access to, and accepts, informal assistance and advice regarding financial management from family, friends, service providers and/or advocates.

Assisted financial management and bill-paying. Examples:

- Person gives someone else regular access to bank records, bills, etc
- Person gives someone else authority to write checks on his account
- Income is deposited directly to an account and basic bills are paid automatically from that account

Restricted bank account. Examples:

- Dual signature account requires two signatures to write a check or make withdrawal
- Accounts limit the size of checks that can be written on the account
- Larger sums are kept in account to which young adult does not have independent access

Restrictions on home ownership. Examples:

- Home paid for and owned by parents, other family members or a trust (young adult may or may not pay rent)
- Home is owned by young adult with ownership restrictions to prevent sale or mortgaging
- Home is owned by young adult but ownership interest or equity is limited by a mortgage, life estate or restrictive covenant
- Person is a joint owner or tenant in common

Durable financial power of attorney. A young adult who is competent can appoint someone else (the *agent*) to manage all or part of the young adult's resources. A durable power of attorney means the document will remain in effect (or go into effect) if the person who signed it becomes mentally incapacitated and is no longer able to handle matters on his or her own.



Court-appointed financial conservator. Young adult can voluntarily request the court to appoint a conservator to hold and manage the young adult's resources. The conservator has the powers of a guardian of estate, but the order is voluntary and there is no finding of incompetence.

Trust funded with family resources (third party trust). Parents, family members, or friends can give their resources directly, or by will, to a designated *trustee* who has a strong legal duty to use the resources for the young adult who is the *beneficiary* of the trust and to use the resources as directed by the trust document. If carried out properly, the young adult gets the benefit of the resources, without ownership and control.

Trust funded with young adult's own funds (self-funded trust). The young adult can voluntarily place his or her own resources in a trust to be used for his or her personal benefit as directed by the trust document. This is a way to have someone else manage the money and to either give up control or to put limits on his or her own ability to make decisions related to the money.

Representative payee for SSI and/or SSDIB benefits. The **Social Security Administration (SSA)** can appoint someone to receive and spend Social Security or **SSI** benefits on behalf of the young adult, on the grounds that the individual lacks capacity to manage benefits or will not apply benefits to own basic support needs. A representative payee only manages the young adult's Social Security or **SSI** funds, and does not otherwise have authority to sign contracts or control the person's finances or decisions.

Court-appointed guardian of estate. Based on a finding of incompetence, a court appoints a competent adult to be a substitute decision-maker for property and finances. This is the most restrictive option, but can be limited to give the young adult some control over decisions, and carried out in a way that respects the person's wishes and abilities while avoiding unacceptable risks. A finding of incompetence requires a finding that the young adult has a mental impairment, does not have capacity to make decisions, and as a result is at risk of not meeting own support needs or is at risk of losing own major resources.

Get More Help...

Wisconsin Board for People with Developmental Disabilities (BPDD) publishes a series of resources on community supported living. One resource is *Making a Difference: Thinking about Decision-Making Support in the Transition Process*. http://www.wi-bpdd.org/publications/2009/making_a_difference.PDF

To learn more go to:

http://www.wi-bpdd.org/publications/pub_by_author.cfm

Guardianship of Adults is a Wisconsin Department of Health Services handbook on guardianship.

To learn more go to:

<http://www.dhs.wisconsin.gov/publications/P2/p20460.pdf>





Meeting needs for decision-making support related to medical care, treatment and autonomy

Identify major concerns:

- Do other people need access to records or other information in order to advise the young adult, talk to providers, or be present when the young adult talks to providers?
- Are health care and support service providers unwilling to provide beneficial treatments and services, which the young adult would accept, because of concerns about the young adult's capacity to give informed consent?
- Does the young adult make health care decisions (or fail to follow recommended treatment) in ways that are significantly detrimental to own health?
- Is the young adult interested in planning ahead for health care decisions, including end-of-life issues, should the young adult be incapacitated, e.g., due to injury or dementia?

Consider the following tools and options:

Release of medical records and information. Releases can be used to provide family members or others with access to health care information. The release may include authority to receive both written and oral information, and to participate in treatment discussions with providers. Releases must be knowing and voluntary, must comply with state law on release of health care or mental health treatment records, and must comply with federal **HIPAA** law, including notice of the right to revoke.

Ordinary health care power of attorney (HCPOA). A young adult who has capacity can appoint an agent to receive health care and mental health treatment information and to make health care decisions on the young adult's behalf if the young adult later becomes incapacitated. *Incapacity* is defined as unable to manage one's own health care decisions due to inability to receive and evaluate information effectively or to communicate decisions. An ordinary **HCPOA** is only effective if it is activated because the person is found to be incapacitated.

Health care power of attorney with special provisions restricting the right to revoke and the right to refuse. This kind of **HCPOA** has special clauses stating that, if the young adult is incapacitated by an acute phase of the young adult's own mental illness, the person wants the health care agent to be able to authorize certain treatments, regardless of the person's refusal of treatment or attempt to revoke the **HCPOA** while incapacitated. (An **HCPOA** of this kind still cannot give an agent authority to admit the person for inpatient mental health treatment over the person's objection.)

Health care power of attorney with special provisions making it effective even when person is not incapacitated. This kind of **HCPOA** adds a provision saying that the young adults wants to give someone else access to health care and treatment records and information, and decision-making authority over health care, even when the person is not incapacitated. If the person has capacity and states wishes, those wishes must be honored, regardless of the agent's consent.



Living will. If competent, the young adult can make a written declaration to physicians directing whether the young adult wants life-sustaining treatment and/or feeding tubes used if the young adult is ever in: (1) a “persistent vegetative state” or (2) a “terminal condition” (i.e., death is imminent and treatment would only postpone moment of death).

Do-Not-Resuscitate Order. A physician can make a written **Do-Not-Resuscitate (DNR) Order** directing emergency medical technicians, first responders and emergency health care facilities personnel not to attempt cardiopulmonary resuscitation on the young adult for whom the order is issued if that person suffers cardiac or respiratory arrest (in-patient hospitals may have a different type of **DNR** orders). The young adult must have a terminal condition, or the physician must find that CPR would be futile or would do more harm than good.

Court-appointed guardian. If the court makes a finding of incompetence, it can appoint another person or agency to be a substitute decision-maker for the young adult’s health care, treatment, support service and other personal (non-financial) issues. A guardian can be appointed based on findings that the young adult has a mental impairment, does not have capacity to make important decisions, and, as a result, is unable to meet the essential requirements to care for own physical health and safety. The guardian only has the powers given in the order that creates the guardianship. These must be limited so the young adults keeps rights and powers the young adult has capacity to exercise.

Court ordered commitment or protective placement. If the young adult refuses to consent to needed treatment for mental illness, or objects to placement in a residential facility, it may be necessary to get a court order for commitment or protective placement.

Get More Help...

Advanced Directives

The following Wisconsin advanced directives forms are available on the Department of Health Services.

- Declaration to Physicians (Wisconsin Living Will)
- Power of Attorney for Health Care
- Power of Attorney for Finance and Property
- Authorization for Final Disposition

To learn more go to:

<http://dhs.wisconsin.gov/forms/Advdirectives/index.htm>

The Wisconsin Guardianship Support Center, part of the Greater Wisconsin Agency on Aging Resources, provides information and assistance on issues related to guardianship, protective placement, advance directives, and more. To learn more call **855 409-9410** or go to: **<http://www.gwaar.org/for-seniors-and-families/elder-law-and-advocacy-center/wisconsin-guardianship-support-center.html>**





Managing assets and resources held by the young adult

Concerns about excess resources:

Excess resources can happen for many reasons, including savings from work, a back payment from Social Security, a settlement in a lawsuit, or an inheritance that was not put into a trust.

- Does the young adult have countable assets in his or her own name that are above the ordinary asset limit for **SSI** or **Medical Assistance**?
- Is the young adult accumulating money because he or she has more current income than expenses?

Consider the following alternatives:

Pay off debts. Pay off any debts, including credit card debts or mortgage loans.

Spend it. There are no limits on how resources can be spent, but there may be penalties if resources are given away or if more is paid for things than they are really worth.

Buy excluded resources. Buy items not counted as a resource, such as furniture, home, computer, car, transportation tickets for future use, and assets connected to burial.

Consider switching to the MA Purchase Plan (MAPP). MAPP helps people who are working continue to be eligible for MA by allowing higher asset levels.

Buy or improve a home, or pay off mortgage. If the young adult owns a share in a home, its value and cost of needed repairs or improvements do not count as a resource.

Put it into education, a business, or a PASS plan. Getting more education or investing in something used in a trade or business can reduce countable resources and raise long-term income. Putting resources into a **Plan to Achieve Self Support (PASS)** allows the young adult to set aside resources for use as part of a plan to reach an employment goal.

Spend it on health, dental or equipment needs for expenses not covered under MA.

Prepay for rent or other expenses. It may be possible to prepay some expenses.

Make an arrangement to put excess resources (or sometimes income) into a special needs trust for young adult. A special needs trust is a way to hold funds for the future benefit of the young adult so the funds do not count as a resource. It is useful if the young adult does not have unmet needs now, but is likely to in the future. If the trust is funded with the young adult's own money, funds left in the trust at the individual's death go to the state (or, in some kinds of trusts, to help other people with disabilities).

Get More Help...

If you are considering prepayment of future expenses, home ownership, or a self-funded special needs trust, you should consult an expert on resource planning for people with special needs. There are many technical requirements, and plans that are not thought through can have unexpected results.



Provision of financial support to the young adult

Concerns about continuing financial support:

- Are you providing financial help to the young adult, and do you want to make sure that help will continue if you are incapacitated or die?
- Do you (or other people) have resources that you would like to set aside to help the young adult, either during your life or when you die?

Consider the following tools and options:

Create a supplemental needs trust. This trust holds resources for the young adult, to be used for the individual's benefit by a *trustee*, who is someone responsible for managing and using the funds. The money placed in this trust can be used flexibly enough to meet future needs, and if the trust is written properly, the money will not be counted as a resource for **Medical Assistance** or **SSI**. This trust allows an individual to provide financial support for the young adult in a way that can continue even after the individual can no longer provide support. Funds remaining in this kind of trust when the young adult dies go to a person designated in the trust and are not subject to any type of recovery by the state. If you do set up a trust, make sure that your will, remainder beneficiary designations, or other estate planning documents are written so that property that would otherwise go to the person instead goes to the trust for his or her benefit.

Create a durable power of attorney for yourself, so that someone has authority to use your resources to benefit the person if you are incapacitated, in the ways that you would if you were still able to make decisions for yourself.

Help the person become a homeowner, or buy a home or condo yourself that you can then use to provide housing for the person.

Help the person live better now, by giving the person furniture, clothing and other exempt resources, paying for transportation, paying for things that will help the person get a better job or have a business, or paying for services.

Create a Letter of Intent that sets out what you know about the person and his or her present and future wants and needs, and that tells your trustees and agents how you want your property used to benefit the person, while at the same time leaving flexibility to deal with the person's changing needs and wants.

Consult an expert on resource planning for people with special needs if you are considering prepayment of future expenses, homeownership, or a supplemental needs trust. There are many technical requirements, and plans that are not thought through can have unexpected results.

Get More Help...

One Step Ahead: Resource Planning for People with Disabilities Who Rely on Supplemental Security Income and Medical Assistance. To learn more go to:
http://www.wi-bpdd.org/publications/2010/OneStepAhead_ThirdEd.pdf





B. Disability Benefits

The following disability benefit information was adapted from the State Department of Health Services website (<http://www.dhs.wisconsin.gov/ddb/>).

Qualifying for disability benefits through Social Security

The **Social Security Administration (SSA)** offers young adults with disabilities the chance to apply for cash payments and public health insurance (public health insurance has several names, including **Medicaid**, Title XIX, and **Medical Assistance** or **MA**). Since rules and eligibility guidelines change over time, this section offers a summary of what may be available. For the most current and accurate information on disability benefits, contact the closest **SSA** office or visit the **SSA** website at <http://www.socialsecurity.gov>. To determine eligibility and to learn more about specific programs that may be available to youth and young adults, directly contact the closest **SSA** office. The **SSA** website may also be used to begin an application for benefits: <http://www.socialsecurity.gov>

Disability determination for purposes of Social Security

The determination of disability for Wisconsin residents is made by the Wisconsin Division of Health Care Access and Accountability, **Disability Determination Bureau (DDB)**.

SSA disability determination is based on the following:

Under age 18 years

- must have physical and/or mental condition that causes severe limitations in the ability to function like other children of the same age
- condition is expected to last 12 months or result in death

Over age 18 years

- must have the presence of physical and/or mental condition that is severe enough to prevent any substantial work activity
- condition is expected to last 12 months or result in death

Get More Help...

National Center for Youth Law has information about the transition from SSI benefits as a child to SSI benefits as an adult.

To learn more go to:

<http://www.youthlaw.org>

ABC for Health is a public interest law firm connecting Wisconsin families with health care.

To learn more go to:

<http://www.safetyweb.org>

State of Wisconsin Medicaid Recipient Hotline is available for Medicaid related questions. To learn more call **800-888-7989** or go to: <http://dhs.wisconsin.gov/medicaid/index.htm>



Monthly cash payment benefits

If the young adult meets the **SSA** disability determination and has limited income and resources, he/she may be eligible for **Supplemental Security Income (SSI)**. **SSI** is a monthly cash benefit paid to people in financial need who are blind or disabled, or are 65 years of age or older.

Turning 18 and SSI

Young adults who receive **SSI** do not automatically qualify for **SSI** as an adult. An adult eligibility determination needs to be made for individuals who are 18 or older. This means that young adults who receive **SSI** need to reapply for the benefit during transition. To prevent interruption of benefits, contact the Social Security office about three months before your 18th birthday.

SSI eligibility is based on the following:

Under age 18 years

- income and resources of the child and family
- child/youth disability determination

Over age 18 years

- income and resources of the adult applicant
- adult disability determination

Social Security Disability Insurance (SSDI)

SSDI is a monthly cash benefit paid to people who have paid into social security and have become disabled and unable to work. Payment amount is based on the actual earnings of the applicant for **SSDI**. It is possible that a young adult may qualify for this benefit. Visit the **SSA** web page (<http://www.socialsecurity.gov/pubs/EN-05-10029.pdf>) or contact your local Social Security office to learn more. For an individual who qualifies for **SSDI**, Medicare takes effect 24 months after this benefit begins.

Social Security Benefits as a Disabled Adult Child

If young adults meet the **SSA** disability determination **and** they have a parent who retires, gets benefits because of a disability, or has died, the young adult may be eligible for benefits based on the parent's work history. Benefits may begin at age 18, and Medicare will take effect 24 months after this benefit begins (but not before age 20). Benefits may be payable to a youth under the age of 18, under some circumstances. Contact the closest Social Security office to learn more about eligibility for this benefit.

Medical Assistance benefits

It is important to know that individuals who qualify for **SSI** automatically qualify for **Medical Assistance (MA)**. Individuals who qualify for **SSDI** or **SSDAC** benefits for two years qualify for **Medicare** coverage.





C. Vocational Rehabilitation

The following information has been modified from the Waisman Center's Healthy and Ready to Work (HRTW) Youth Fact Sheets

<http://www.waisman.wisc.edu/ucedd/prod-youthfactsheets.htm>

Getting help to get a job

The **Division of Vocational Rehabilitation (DVR)** helps people with disabilities get a job. It is a federal/state program designed to obtain, maintain, and improve employment for people with disabilities. To make this happen, **DVR** works with consumers, employers, and other partners.

Eligibility for DVR services

Eligibility for DVR services require that young adults must have a disability that gets in the way of getting or keeping a job. Common types of disabilities are: attention deficit disorder, cerebral palsy, deafness, blindness, depression, specific learning disability, traumatic brain injury, or para/quadruplegia. There may be a wait to receive services. **DVR** serves people with the most significant disabilities first. If there is enough money, they then serve people with less significant disabilities.

DVR can provide a number of services

Helping young adults find a job that works for them through:

- career counseling to help identify a career goal
- assessments to identify individual skills
- help finding a job
- help creating a resume

In some cases, helping pay for job-associated costs for:

- mobility training
- appropriate work clothes
- academic accommodations at college (for example, tutoring)

Help begins with an Individual Plan for Employment

Before young adults receive services, they create an **Individual Plan for Employment (IPE)** with their counselor. The young adult and counselor must both agree to the plan. The plan says what the young adult's job goal is and the services he/she will need to get that job. It is helpful if young adults already know what they are good at (their skills) and what they are interested in doing for work. The **IPE** also says who is responsible for paying for the services.



Sometimes help is available for attending a technical college or university

DVR is not a scholarship program. It is a federally funded-program to assist people with disabilities who want to work get the skills they need to become employed. Depending on the situation, young adults may be able to receive financial help with tuition, books and disability-related services (like tutoring and homework aides). Young adults must apply for financial aid with the college or university before **DVR** will consider paying for any college expenses. Then **DVR** may provide financial help with college expenses if this leads to young adults getting a job they are interested in and qualified to do.

How to apply for DVR services

A counselor can explain **DVR** services, help determine eligibility for services, and fill out an application with young adults who want to apply. If there is a waiting list, **DVR** helps people first who have the earliest date on their application. To apply, young adults need to provide documentation of a disability. The application process can be quicker and easier if the documentation of disability and addresses of doctors are available when the application is made.

Building a relationship with the DVR Counselor

The process of finding and keeping a job is much easier when young adults receiving services build a relationship with their **DVR** counselor. Young adults can call or e-mail their counselor regularly with updates about their progress or what they need. Young adults can also build a positive relationship with their **DVR** counselor by providing information that the counselor will need in a timely manner. A positive relationship is also built by asking questions and telling the counselor about individual needs, such as academic accommodations, work accommodations, help looking for a job, or help identifying a possible job.

Get More Help...

Division of Vocational Rehabilitation (DVR) offices have counselors who can explain eligibility and how to apply. To learn more call **800-442-3477** or go to: <https://dwd.wisconsin.gov/dvr/>

Client Assistance Program (CAP) can help young adults understand their rights and the policies of **DVR**. To learn more go to: <http://dwd.wisconsin.gov/dvr/cap.htm> Young adults can appeal to **CAP** if they disagree with a decision made by their counselor. **CAP** also offers mediation. To learn more call: **800-362-1290**.

Department of Public Instruction offers the *Opening Doors to Employment* booklet. To learn more go to:

<http://pubsales.dpi.wi.gov/product/opening-doors-to-employment>

DHS, DPI, DWD Transition Interagency Agreement is a guide on how these three agencies partner around transition.

To learn more go to:

http://dwd.wisconsin.gov/dvr/pdf_files/dpi_interagency_agreement.pdf





D. Work and Disability Benefits

The following disability benefit information was adapted from the Wisconsin State Department of Health Services website (<http://dhs.wisconsin.gov/medicaid/>).

Section 301 – Provision to Continue Receiving Social Security Administration (SSA) Benefits

Section 301 of the Social Security law can be used when a young adult, at age 18 years no longer meets **SSA** medical qualifications. Young adults who receive **SSA** cash benefits and also work can continue to receive **SSI** and **SSDI** benefits as well as **Medicaid** or **Medicare** coverage if:

- they are participating in an approved vocational rehabilitation program prior to age 18
- OR**
- they have an active **IEP**

Ticket to Work

The **Ticket to Work** program is part of **SSA**. It is for people receiving Social Security benefits because of a disability. It can help those individuals who receive disability benefits and have a work goal. The program offers more choices in getting the services needed to go to work and earn money. The goal is to earn enough money so Social Security cash benefits are not needed.

Employment, vocational, and other services are available through Employment Networks (private organizations or government agencies). Agencies in the Employment Networks have agreed to work with the **SSA** to provide employment services to beneficiaries with disabilities. A ticket allows the person receiving **SSI** or **SSDI** to choose which of these agencies to work with.

To be eligible for Ticket to Work:

- must be over 18 and under 65
- must have a disability as determined by **SSA adult disability standard**.

To learn more go to: <http://www.yourtickettowork.com>

Work Incentive Benefits Counseling (WIBC) **WIBC** is a service available to youth who get **SSA** cash payments and want to work. The **WIBC** service can help youth understand the impact earning money from work will have on **SSA** cash payments, and provide guidance on how to take advantage of the work incentives available to **SSDI** and **SSI** beneficiaries. For individual assessment, contact a local Work Incentive Benefits Specialist. To learn more go to: <http://www.wibsa.org/membership/find-a-member/>



E. Medicaid in Wisconsin

The following disability benefit information was adapted from the State Department of Health Services website: (<http://dhs.wisconsin.gov/medicaid/>).

Wisconsin Medicaid/BadgerCare Plus

Medicaid is a public insurance program that pays for health care services, funded by both the federal government and the Wisconsin Department of Health Services (DHS), and has a set of benefits associated with it. In Wisconsin, the program is also referred to as: BadgerCare Plus, Medical Assistance (MA), Title XIX and/or Title 19. Medicaid eligibility can be based on the family's income and/or the child's level of disability.

Young adults with a physical disability, developmental disability, or medical condition that significantly affects daily living or functioning may be eligible for a **Medicaid** plan listed below.

- **Medicaid**—a plan for people who are age 65 or older, blind or disabled
- **Medicaid Purchase Plan**—a plan for people with disabilities who work
- **Family Care**—a long term care program for people who are age 65 or older, or have physical or developmental disabilities
- **Family Care Partnership (Partnership)**—a program that adds medical care to the long-term support services in Family Care
- **IRIS**—a self-directed long-term care option which helps Wisconsin elders, adults with physical disabilities and adults with developmental disabilities who are Medicaid eligible are included in the community
- **Community Waivers**—a program that help elderly, blind or disabled people live in their own homes or in the community, rather than a state institution or a nursing home
- **BadgerCare Plus**—The BadgerCare Plus program offers affordable healthcare coverage to low-income children and families.

Due to provisions in Wisconsin's 2013-2015 State Budget, childless adults with incomes under 100% of the Federal Poverty Level (FPL) are to be eligible for BadgerCare coverage. The date of effectiveness of this provision is uncertain as of this time. For the most current and detailed information about Medicaid and BadgerCare in Wisconsin, please go to <http://www.dhs.wisconsin.gov/medicaid> or <http://www.dhs.wisconsin.gov/badgercareplus/>

Wisconsin Medicaid eligibility is based on the following:

- must have a disability as determined by the **Disability Determination Bureau (DDB)** **OR** be 65 years of age or older
- must be a Wisconsin resident
- must be a US citizen or qualifying immigrant
- must meet the income limits for the program





Wisconsin Medicaid eligibility is automatic for people who qualify for SSI

- in Wisconsin, **SSI** recipients automatically get **Medicaid** coverage

Medicaid Purchase Plan (MAPP)

MAPP can allow individuals to remain eligible for **Medicaid** when they work. **MAPP** has higher asset and income limits than other forms of **Medicaid**. **MAPP** recipients can also save more than the asset limit by using a registered Independence Account. Some individuals pay a premium, which is based on the individual's income level.

MAPP eligibility is based on the following:

- must qualify for **Medicaid** based on the eligibility criteria listed above
- be at least 18 years old
- engage in work activity once per month
OR be enrolled in the **Health and Employment Counseling (HEC)** program
- have less than \$15,000 in assets

Family Care

Family Care is a long-term care program that serves people with physical and developmental disabilities as well as frail elders. It is not currently available in every county.

Family Care has several goals:

- giving people better choices about where they live and what kinds of services and supports they get to meet their needs
- improving access to services
- improving quality through a focus on health and social outcomes
- creating a cost-effective system for the future

Family Care has two major parts:

- 1. Aging and Disability Resource Centers (ADRCs)** are a single entry point where older individuals, and individuals with disabilities and their families, can get information and advice about services and resources in their local communities. **ADRC** services are available to everyone, regardless of eligibility for **Family Care** or **Medicaid** programs. To learn more go to: <http://www.dhs.wisconsin.gov/LTCare/adrc/index.htm>
- 2. Managed Care Organizations (MCOs)** manage and deliver the new **Family Care** benefit. To learn more go to: <https://www.dhs.wisconsin.gov/familycare/mcos.htm>

Services are based on each person's needs and preferences.

Family Care eligibility is based on the following:

- must have long-term care service needs
- must be an older adult or an adult with a developmental or physical disability
- must live in a county that is offering **Family Care**
- must meet financial eligibility requirements



Family Care Partnership (Partnership)

Partnership is a **Family Care** program that provides a full range of long-term care, health and medical services, and prescription drugs to enable people to live as independently as possible. Long-term care is any service or support that individuals may need as a result of a disability, getting older, or having a chronic illness that limits the ability to do the things that they need to do throughout the course of the day. This includes things such as bathing, getting dressed, making meals, going to work, paying bills, and much more. There are a variety of services and supports available in **Partnership** that can help people do these things independently or with the support of someone else.

Partnership also covers health and medical services, including the services of a physician, nurse practitioner, physician assistant, or other qualified medical professional. Health promotion, disease prevention, health maintenance, and patient education are also provided. In addition, **Medicaid** and **Medicare** drug services are all provided by the Family Care **Partnership** organization. Members do not need to have a separate Medicare Part D drug plan. By coordinating long-term care, health, medical care, and prescription drugs all together, this program is convenient and efficient for its participants.

Include, Respect, I Self-Direct (IRIS) is a Wisconsin program where you self-direct your publicly funded, community-based, long-term care supports and services. If an individual qualifies for long-term care in Wisconsin, and if Family Care is available, then the individual can choose whether to have Family Care or **IRIS**. In **IRIS** you use your own natural supports and creativity with your budget to achieve your hopes and dreams. To learn more go to: <http://www.dhs.wisconsin.gov/bdds/iris/>

Get More Help...

Medicaid plans and program details are available to you.

To learn more on how to apply for **Medicaid** at the local county or tribal human service agency go to: <https://access.wisconsin.gov/access/>

Family Care Ombudsman at Disability Rights Wisconsin (DRW) can assist people with disabilities in the Family Care and Partnership programs, the Legislature has funded a Family Care Ombudsman Program for people under age 60. To learn more go to:

<http://www.disabilityrightswi.org/programs/fcop>

Department of Public Instruction offers the *Opening Doors: A Guide to Adult Services* booklet.

To learn more go to:

<http://dpi.wi.gov/files/sped/pdf/tran-adult-services-guide.pdf>





Community Waivers

Waivers occur when the federal government waives certain **Medicaid** rules. The purpose of all **Community Waivers** is to allow the state to support people in the community instead of in institutions. Programs are administered by county agencies. In Wisconsin, **Community Waivers** are available in counties not yet participating in **Family Care**. In most counties there is a long waiting list for waivers. So it is important to apply as soon as it is apparent that these services may be needed. Eligibility is based on functional need for long-term care, low-income and asset financial requirements similar to **Medicaid**.

Brain Injury Waiver (BIW)

This waiver program provides home- and community-based services for people with brain injuries who need significant supports.

BIW eligibility is based in part on the following:

- must be eligible for **Medicaid**
- must meet the state definition of Brain Injury
- must have, as a result of the brain injury, significant physical, cognitive, emotional or behavioral impairments and be eligible to receive post-acute rehabilitation services

<http://dhs.wisconsin.gov/bdds/brain.htm>

Community Options Program Waiver (COP-W)

Frail elderly and persons with physical disabilities at risk of entering a nursing home receive funds and assistance to find community services not available through other programs.

COP-W eligibility is based in part on the following:

- must be eligible for **Medicaid**
- must be age 18 and over with a qualifying physical disability determination **OR** must be age 65 and over and with a long-term or irreversible illness or disability that impairs daily functioning

http://dhs.wisconsin.gov/ltc_cop/COP.HTM

Community Integration Program (CIP IA and CIP IB, and CIP II)

Persons with developmental disabilities who are relocated from state institutional care (**CIP IA** and **CIP IB**) receive funds for community-based services. The **CIP II** waiver provides community services to frail elderly and persons with physical disabilities after a nursing home bed is closed.

CIP IA, IB, or II eligibility is based in part on the following:

- must be eligible for **Medicaid**
- must have developmental disability (**CIP IA** and **CIP IB**) **OR** physical disability (**CIP II**)

<http://dhs.wisconsin.gov/bdds/cip/index.htm>





BadgerCare Plus in Wisconsin

BadgerCare Plus provides affordable healthcare coverage for low-income children and families in Wisconsin. Currently changes are underway with BadgerCare Plus. Please visit <http://www.dhs.wisconsin.gov/badgercareplus/> for accurate, up-to-date information.

BadgerCare Plus eligibility is based on income and on the following criteria:

- must live in Wisconsin
- must provide proof of citizenship and identity

Apply for **BadgerCare Plus** online: <https://access.wisconsin.gov>, or contact the local tribal or county human services agency. A local phone directory will provide the contact information for the local human services agency.





F. Health Insurance:

Private Insurance and the Health Insurance Marketplace

As a young adult preparing to become more independent in the area of health care, it is important to know your insurance coverage choices. Private insurance and employer-sponsored coverage may be possibilities for you. With the implementation of the Affordable Care Act (ACA) and the opening of the health insurance marketplace, there are new considerations that may affect you.

Coverage Options for Young Adults

Continued benefits under a family's private health insurance plan

Young adults may remain on their parents' health insurance plans until age 26 when there is family coverage.

Adult Disabled Dependent Child

Young adults who are dependent, and who are also being financially provided for by their parents, may be eligible to continue on their family's plan. This may be affected by federal and/or state law. If you are considering this option, it is very important to check with your insurance company to learn how your plan is governed—by federal or state regulations. It is also important to understand the specific requirements to be considered a dependent.

Student Health Plans

Young adults who are in post-secondary school (technical school, college) may have access to health insurance plans through these institutions. This often requires full-time student status. It also requires providing proof of class load each semester and annual re-certification.

Employer-based insurance

Some young adults may have jobs with benefits that include employer-based insurance.

COBRA

COBRA coverage applies to those who have lost their jobs and still wish to maintain their employer-based insurance coverage for up to 18 months. This usually applies to group health plans from employers with 20 or more employees. COBRA coverage may cost more than other options because the employer does not pay a share of the insurance premium.

Affordable Care Act (ACA)

Young adults may purchase insurance through the health insurance marketplace. Depending on income, young adults may also be eligible for assistance to pay for this coverage in the form of a premium subsidy or a tax credit. For more information on plans and costs, please go to www.healthcare.gov.



Additional Factors to Consider

As you consider which option will give you the most comprehensive health coverage, think about the following provisions of the ACA:

- Insurance companies may not deny coverage based on pre-existing conditions for children, nor—as of January 1, 2014, for adults.
- Young adults may remain on their parents' plans until age 26 if family coverage is available.
- Insurance companies can no longer impose annual or lifetime benefit caps.
- There are limits on out-of-pocket expenditures related to family coverage.
- Certain types of preventive care must be provided for free, with no copays or deductibles. For a list and details, please go to <https://www.healthcare.gov/what-are-my-preventive-care-benefits/>

Get More Help...

The Affordable Care Act and You: What Your Family Needs To Know

To learn more go to:

<http://www.aap.org/en-us/advocacy-and-policy/Documents/Map/Universal.pdf>

Healthcare.gov has information on the **Affordable Care Act**, and applying for federal marketplace coverage.

To learn more go to:

<http://www.healthcare.gov>

Enrollment for Health (E4H) Wisconsin has health insurance plan options for consumers.

To learn more go to:

<http://enrollwi.org>

The Wisconsin Office of the Commissioner of Insurance Fact Sheet on Mandated Benefits in Health Insurance Policies (see page 2, Covered Persons, Handicapped Children).

To learn more go to:

http://oci.wi.gov/pub_list/pi-019.pdf

Glossary of Health Coverage and Medical Terms

To learn more go to:

<http://www.cms.gov/CCIIO/resources/files/downloads/uniform-glossary-final.pdf>

The **Catalyst Center** has information and resources on health coverage for children/youth with special health care needs.

To learn more go to: <http://www.hdwg.org/catalyst/>

ABC for Health has information and resources about health benefits topics.

To learn more go to:

<http://www.safetyweb.org/resources.html>

Family Voices of Wisconsin has information on health care reform. To learn more go to:

<http://www.familyvoicesofwisconsin.com/resources/affordable-care-act/>





G. Assistive Technology

The following assistive technology information was adapted from the 2008 Pennsylvania Transition Health Care Checklist.

What is assistive technology?

Assistive Technology (AT) can be any item, piece of equipment, product or system whether acquired commercially, modified or customized that is used to increase, maintain or improve functional capabilities of individuals with disabilities. It can be a device, but it can also include any services needed to locate and learn how to use the tools including evaluation, customization, maintenance, repair and training for the user and those who support him or her.

- **Devices for work or school:** Devices or software that enlarge print or read text, voice dictation or word prediction software, portable computer or keyboards, tablets, TTY devices, alternative or hands free mouse, alternative keyboards, specialized writing devices, communication devices, (also known as **Speech Generating Devices-SGD**), computer based drawing and graphic programs, specialized apps for tablets or smartphones, or specialized calculators, probes and measuring devices, adapted tools such as jigs that can help with specific work tasks.
- **Devices for community living:** Changes to a home or vehicle that enable individuals to get around better, such as ramps for access, shower chairs, tablet app or voice activated light/heat controls, railings in tubs or around toilets, modified faucets, lower counters, lifts, specialized cooking equipment, jigs for job related tasks, visual cueing for doorbells, phones and buzzers, sound or global positioning system (GPS) based guidance systems and talking measuring tools.
- **Devices for recreation:** Three-wheeled adult bike, adapted sports equipment including wheel chairs, adapted hand and foot tools for amputees, bi- skis, adapted seating for access to riding activities, adapted grips/ supports for golf clubs, bats or painting/carving tools, verbal or visual prompts for balls, magnifiers or jigs that can hold tools, materials for projects, specialized lighting or any tools that allow participation in recreation activities.

AT in education and work environments

AT must be considered as part of the Individualized Education Program (**IEP**) process for students in the K-12 school system because of federal and state requirements (**IDEA**).

Once young adults leave high school, **AT** is included in the **Americans with Disability Act (ADA)** legislation for post-secondary school and work environments. However, young adults who are finished with high school and need **AT** have the responsibility to request and learn to use the **AT** themselves. All public colleges and many private colleges and technical colleges have a department to address and support the needs of students with disabilities. These departments may be a good resource for **AT** tools needed for college classes.

Other resources for help may include the **Division of Vocational Rehabilitation (DVR)**, employers, or the Internet. If **AT** is needed for employment, the young adult and his or her **DVR** counselor can consider including **AT** in the **Individualized Plan for Employment (IPE)**.



Learning about Assistive Technology (AT)

Because young adults will be responsible for knowing what **AT** they need and obtaining the devices themselves once they leave high school, exploring the range of tools while in the K-12 school system is a great idea. School districts may have resources related to how to access and use **AT** devices and should consider the following:

- the **IEP** team can borrow equipment from lending libraries available to the school so students can try an item before buying
- the **IEP** team should consider what tools and services students need and help students learn to use them
- the school or regional **Cooperative Educational Service Agency (CESA)** may have staff that are knowledgeable about **AT** options and can assist your **IEP** team in planning for students' current and future **AT** needs

If you are planning to use AT, remember that it is important to have a good match between the AT and your needs. You may wish to seek the assistance of professionals with training in AT to make that match, and so you can learn how to use the AT well.

Identifying and obtaining AT

Individual user needs should be considered when identifying **AT** options, as well as what the tool needs to do and the places the tool will be used. A process that can help with identifying the **AT** that will be helpful to a user is known as Student/Environment/Task / Tool (**SETT**). This process gives consideration to both the tasks that need to be done and the **environment** in which tasks need to be completed. Once a device is identified, it can be helpful to try it out before making a purchase, especially because some devices are expensive. Consider the following:

- product vendors may offer trial periods with their products to make sure they work, especially expensive items like communication devices and switch arrays
- some insurance companies, **MA**, or **DVR** may be willing to pay for AT. It is important to check with your state MA program, with your Medicaid/BadgerCare HMO, and/or with your insurer as to their specific AT coverage policies.
- employers may be willing (or sometimes are obligated) to provide assistive technology to employees to comply with **ADA** if the **AT** is considered a reasonable job accommodation
- in some circumstances, helpful technology may be available at no cost, such as free or open source software (text readers, organizers, etc) that is available on the internet
- unfortunately computers are generally not considered **AT** from most funding sources, other than K-12 schools, despite the wide array of software tools that can support employment and further schooling

Get More Help...

CESA Assistive Technology (AT) services available to the school district may include assessment support, loaning tools, and team support. If the **IEP team** seems unfamiliar or uncomfortable with **AT**, the **CESA** can be a resource. To learn more go to: <http://www.wati.org/?pageLoad=content/services/at/index.php>

Wisconsin Assistive Technology Program (WisTECH) WisTech is **AT** program that provides information on selecting, funding, installing and using **AT**. To learn more go to: <http://www.dhs.wisconsin.gov/disabilities/wistech/index.htm>





H. Mental Health Services

The following information on mental health was adapted from the Mental Health and Substance Abuse Collaborative Pilot.

Wisconsin has a county-based mental health system in which each county determines what services to offer. If you do not have private insurance, you can contact the human services department in your county to learn more about what is available locally and how to apply for services for yourself or your child.

Start with a diagnostic evaluation

If you believe that you or your child has a mental health problem, the first step is to seek an evaluation to determine if a diagnosis is appropriate. Your primary provider may be able to provide a diagnosis or refer you to a qualified evaluator. Your county human services department can identify qualified evaluators in your area.

If you or your child needs services that are more intensive than out-patient visits, your county might provide the following services:

- **Comprehensive Community Services (CCS)** programs provide an array of individualized services to individuals of any age with mental health or substance use issues that impair his/her ability to participate in community life. The CCS staff assist individuals to identify formal and informal supports and coordinate services to support a fuller recovery. Individuals qualify for CCS if they need a higher intensity level of services than outpatient mental health services and less intensity than the Community Support Program (CSP).
- **Community Recovery Services (CRS)** programs enable people with mental illness, aged 14 and over, to live with maximum independence within the community. CRS services enable individuals to better manage their illness, to increase their independence, and to reduce their hospitalizations for mental illness. The three categories of services available from CRS include community living supportive services, peer supports and supported employment.
- **Community Support Program (CSP)** programs provide intensive support services for individuals who have a severe and persistent mental illness and are living in the community. The CSP team provides coordinated care and treatment services that are intensive, accessible, community based mental health treatment and psycho-social rehabilitative services. CSP programs “wrap” individualized services around the individual and flexibly adapt to the individual’s needs in the recovery process.



- **Coordinated Services Teams (CST)** provide support to minors with significant needs and their families regardless of whether the family has private insurance. Eligibility is restricted to children involved in at least two systems of care (for example, mental health, special education, child welfare, juvenile justice) and emphasis is on children diagnosed with severe emotional disturbance. In this model of wrap around services, teams usually include the child, parents/guardians, natural supports, service providers and others identified by the family. The teams focus on supporting children and families through a process that includes individualized assessments of strengths and needs, development of a plan to support these and a crisis plan to minimize the effects of crises.
- **Crisis Intervention Services** are available 24-hours a day, every day, to people experiencing a crisis (or a situation that might develop into a crisis) due to an apparent mental health or substance use disorder. When a high level of stress or anxiety cannot be resolved by available coping methods or ordinary care and support, Crisis Services can provide a range of immediate supports, including specialized services for children, adolescents and their families. Crisis intervention services can be provided over the phone or in person, and may include services to assist in managing future crises through assessment and planning.

To learn more about the mental health programs described above go to:
http://dhs.wisconsin.gov/MH_BCMH/index.htm

Get More Help.....

Wisconsin Families Ties is a statewide not-for-profit organization run by families for families that have children and adolescents who have emotional, behavioral, mental and substance abuse disorders. To learn more call 608-267-6888 or 800-422-7145 or go to: <http://www.wifamilyties.org/>

Wisconsin-State Resource Guide

To learn more go to:

[http://store.samhsa.gov/shin/content/SG-WI/SG-WI.pdf](http://store.samhsa.gov/shin/content/SRG-WI/SG-WI.pdf)

National consumer agencies

To learn more go to:

<http://store.samhsa.gov/mhlocator>

AACAP's Facts for Families provide information about mental health and specific conditions.

To learn more go to:

http://www.aacap.org/AACAP/Families_and_Youth/Facts_for_Families/Home.aspx

National Alliance on Mental Illness (NAMI) is the nation's largest grassroots mental health organization dedicated to building better lives for the millions of Americans affected by mental illness.

To learn more go to:

<http://www.nami.org>





I. Youth Health Care Transition

The following is a UW Health, Health Facts For You.

Getting Started

What is Youth Health Care Transition?

Knowing what youth health care transition is all about is the first step. It is the process of moving from pediatric to adult health care. This process takes time. During this time you will get support while you learn and practice skills you need to be independent. Transition includes inpatient and outpatient primary and specialty care. Planning for transition is based on you and your family's needs. Some youth with complex medical, health, or other special needs, need more help than others. Our goal is for you to get the support you need to reach your full potential. Family, friends, schools, communities and primary care providers will help you to succeed.

Working with Your Health Care Team

As I begin to transition what are some of the questions I can ask my doctors?

You are a partner in your health care and have the right to ask for what you want. If you are not sure about what you want, talk with your health care team. Below are some sample questions that you and your parents can ask your doctor to get the conversation started:

- At what age does this clinic transition youth to adult care?
- If I am in a family practice clinic do I need to think about health care transition?
- Can you suggest an adult provider for me?
- Can you help me with transition planning? Do you have transition care plans that you use?
- What community resources should I learn about?

What are some tools that can help me and my family as I transition?

You and your family are partners with the health care providers on your team. As a team you can create and use a written transition plan. This helps the members of your team keep track of the steps; know who is doing what, and when certain things need to be done. A sample transition plan will include the following:

- A list of your pediatric doctors and health care providers by clinic and a space for an identified adult provider in that health area.
- A timeline for moving from pediatric to adult care for each health area.
- A timeline for writing a medical summary that will be given to the doctor.



To find sample transition plans go to: <http://wimedicalhometoolkit.aap.org/transitions/> or you can ask your doctor what plan to use.

How will I know if the transition process is going well?

You may want to evaluate the transition process. You and your team can decide how often to do this. There are many ways to evaluate the process.

- Use checklists found in the sample plans.
- Plan routine check-in with the health care team to review the plan. At this time you can decide if the process is going smoothly or if there are problems to talk about.
- Keep learning more about transition. Keep in mind it is a process, not an event.

Gathering Information

What do you need to know to get ready for transition?

There are some legal changes that happen starting at ages 12, 14 and 18. Below are some examples of changes that you may notice:

- Your doctor may ask your parents to leave the room. This is so you can have a private and sometimes confidential talk with your doctor.
- Your Insurance coverage may change. This depends on whether you are covered under your parents insurance plan, or if you have your own insurance through Medicaid.
- Legal rights for you and your parents change unless you take action.
 - Access to medical information and decision-making.
 - Authorization for Verbal Communication form.
 - Power of attorney, guardianship, advance directive.





Where can my parents and I go for more information about resources for me as a youth special health care needs?

You can talk with your health care team, and check out these resources:

- The Southern Regional Center for Children and Youth with Special Health Care Needs has resource specialists ready to help with questions: <http://www.waisman.wisc.edu/cshcn/>
- The Waisman Center has health transition materials that you can download: <http://www.waisman.wisc.edu/cedd/products.php>
- *Crossing the Bridge to Adulthood* reviews transition for youth with special needs: http://www.chw.org/display/displayFile.asp?docid=43716&filename=/Groups/ClinicalResources/Conferences/Crossing_the_Bridge_to_Adulthood.pdf
- Health Transition Wisconsin is a toolkit of resources www.healthtransitionwi.org
- If you have a specific health condition or disability, search the web for condition-specific transition tools.
- The National Health Care Transition Center has many web-based resources for youth, families and providers: <http://www.gottransition.org/>

Practicing Independence Skills

What can my parents do to help me be more independent?

From an early age they give you guidance and messages to help you look forward to life as an adult. Below are some simple ways they can help you learn skills to be independent.

- Learn coaching skills to help them talk with you and teach you about your medical condition.
- Give you chores around the house.
- Gently remind you that one day you will be an adult.

What skills do I need to be independent?

Everyone is unique and the level of independence you reach will vary. You and your family can think about what it would look like for you to reach your full potential. You may communicate with words, or you may use sign language, writing, communication devices, pointing, story boards or other methods. You and your family can talk about ideas for you to gain skills.



Here are some ways you can practice independence at home, school and in your community.

- Know how and when to ask for help.
- Find a way to tell others about your health condition.
- Find a way to name medicines you are taking and why.
- Bring your medical history or personal health record to a doctor visit using one of these tools.
 - smart phone
 - tablet
 - paper
 - flash drive
- Write health independence goals into a 504 health plan or an Individualized Education Program: <http://www.waisman.wisc.edu/cshcn/cdrom.php>
- Write your own health plan if a formal health plan is not available.

At your doctor's office you can practice independence through these skills:

- Ask for time for you and your doctor to talk with each other.
- Ask for time for you and your doctor to meet alone for part or all of an office visit
- Call in prescriptions refills first with the help of a parent or caregiver. Work towards doing this on your own.
- Schedule a doctor appointment first with the help of a parent or caregiver. Work towards doing this on your own.
- Use tools to help you remember questions and your doctor's recommendations. Write on paper, or use an electronic device, email, voice record, or after visit summary.





Additional Resources

Advocacy and Resource Organizations

ABC for Health is a public interest law firm connecting Wisconsin families to health care. <http://www.safetyweb.org>

Disability Rights Wisconsin helps people across Wisconsin gain access to services and opportunity through its advocacy and legal expertise. <http://www.disabilityrightswi.org/>

Family Voices of Wisconsin strongly believes in the strength of parent/provider partnerships and works to advance the knowledge and skills of families as they navigate health care and community supports for children and youth with disabilities and/or special health care needs. <http://www.familyvoicesofwisconsin.com/>

Independent Living Centers provide consumer driven services and promote full participation in society for people with disabilities. Services include peer support, information and referral, independent living skills training and advocacy. <http://www.dhs.wisconsin.gov/disabilities/physical/ilcs.htm>

National Center for Youth Law works to ensure that low-income children have the resources, support, and opportunities they need for a healthy and productive future. <http://www.youthlaw.org>

The **Waisman Center** supports the full inclusion and self-determination of people with developmental disabilities and their families. The Center accomplishes this mission through its research and preservice training programs, clinical and intervention services, continuing education programs, technical assistance and consultation services. <http://www.waisman.wisc.edu>

Wisconsin Board for People with Developmental Disabilities (BPDD) helps people with developmental disabilities become independent, productive, and included in all facets of community life. <http://www.wi-bpdd.org/>

WI FACETS is a nonprofit organization that provides training, information and referral, and individual assistance related to special education and IEPs. <http://www.wifacets.org>

Wisconsin Family Ties is a statewide not-for-profit organization run by families for families that include children and adolescents who have emotional, behavioral, mental, and substance abuse disorders. <http://www.wifamilyties.org/>

Wisconsin Guardianship Support Center, is part of the Greater Wisconsin Agency on Aging Resources, and answers questions about the law in Wisconsin relating to guardianships, protective placements, conservatorships, Powers of Attorney for Health Care, Living Wills, DNR orders, and Powers of Attorney for Finances. <http://www.gwaar.org/for-seniors-and-families/elder-law-and-advocacy-center/wisconsin-guardianship-support-center.html>





State Agencies and Programs

Wisconsin Department of Health Services (DHS)

Within this Department there are several programs which support individuals with long-term care needs. A complete list of benefits available to Wisconsin residents who have a disability and/or mental health needs, is on the website.

<http://www.dhs.wisconsin.gov>

Children and Youth with Special Health Care Needs Program

Wisconsin has five **Regional Centers for Children and Youth with Special Health Care Needs** that assist callers with questions and resources.

<http://www.dhs.wisconsin.gov/cyshcn/regionalcenters.htm>

First Step is a 24-hour public health information and referral hotline for children and adolescents age birth to age 21 with special needs. WI First Step serves families and professionals.

800-642-7837 (toll free); online resource database:

<http://www.mch-hotlines.org>

Great Lakes Intertribal Council's Children and Youth with Special Health Care Needs Project provides information, resources and assistance to Native American families of children with special needs.

<http://www.glitc.org/programs/cyshcn/>

Medical Assistance

ACCESS

ACCESS is a quick and easy way for people in Wisconsin to get answers to questions about health and nutrition programs. Apply for **Medicaid** programs online at <https://access.wisconsin.gov/access>, or contact the local tribal or county human services agency. A local phone directory will provide the contact information for the local human services agency.

Aging and Disability Resource Centers (ADRCs)

ADRCs are service centers that provide a place for the public to get accurate, unbiased information on all aspects of life related to aging or adult living with a disability.

<http://www.dhs.wisconsin.gov/adrc/index.htm>

Community Waivers:

Medicaid Community Waivers Plan helps people who have disabilities to stay living in the community.

<https://www.dhs.wisconsin.gov/library/P-10059.htm>



Family Care is an adult long-term care program in many Wisconsin counties.

<http://dhs.wisconsin.gov/LTCare/INDEX.HTM>

Current county list available:

<http://www.dhs.wisconsin.gov/familycare/index.htm>

IRIS is Wisconsin's self-directed supports program for older people and for adults with disabilities who are **Medicaid**-eligible.

<http://www.dhs.wisconsin.gov/iris/index.htm>

Medicaid Plan and program details are available:

<http://www.dhs.wisconsin.gov/medicaid/index.htm>

Wisconsin Department of Public Instruction

Within this Department, the Division for Learning Support: Equity and Advocacy addresses the needs of students with special education needs through the following:

Special Education Team, Student Services, Prevention, and Wellness Team, Wisconsin Educational Services Program for the Deaf and Hard of Hearing, Delavan, and Wisconsin Center for the Blind and Visually Impaired, Janesville.

<http://dpi.wi.gov/dls>

Each **Cooperative Educational Service Agency (CESAs)** has a designated transition coordinator who works with every school district in its area.

<http://www.cesawi.org/contact/>

Transition Improvement Grant (TIG) within the Department of Public Instruction, provides professional development to Wisconsin youth, parents, educators and all stakeholders in the area of postsecondary transition.

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

The **Wisconsin Statewide Parent-Educator Initiative (WSPEI)** is a service for parents, educators, and others interested in parent-educator partnerships for children with disabilities.

<http://wspei.org/>





Wisconsin Department of Workforce Development

The **Wisconsin Department of Workforce Development (DWD)** is a state agency charged with building and strengthening Wisconsin's workforce, include providing job services, training and employment assistance to people looking for work.

Division of Vocational Rehabilitation (DVR)

DVR has embraced the concept of teaming as a way for all staff to work together toward common goals and to achieve the mission: To obtain, maintain and improve employment for people with disabilities by working with Vocational Rehabilitation consumers, employers and other partners. A counselor can explain eligibility and how to apply.

800-442-3477

<http://dwd.wisconsin.gov/dvr/>

Client Assistance Program (CAP)

The **Client Assistance Program (CAP)** can help young adults understand their rights and the policies of **DVR**. Young adults can appeal to **CAP** if they disagree with a decision made by their counselor. **CAP** also offers mediation.

800-362-1290

<http://dwd.wisconsin.gov/dvr/cap.htm>

Wisconsin Interagency Agreement and Transition Action Guide for Post-School

The purpose of this DPI/DVR/DHS Interagency Agreement is to fulfill the interagency agreement mandates found in the Individuals with Disabilities Education Act and the Rehabilitation Act and to coordinate services for individuals transitioning from education to employment.

http://dwd.wisconsin.gov/dvr/pdf_files/dpi_interagency_agreement.pdf



Glossary of Abbreviations and Acronyms

ACA	Affordable Care Act
ADA	Americans with Disabilities Act
ADRC	Aging and Disability Resource Center
AT	Assistive Technology
BIW	Brain Injury Waiver
CCS	Comprehensive Community Services
CESA	Cooperative Educational Service Agency
CAP	Client Assistance Program
CIP	Community Integration Program
CM	Care Manager (also referred to as support and service coordinator, or case manager)
CMO	Care Management Organization (a term often used to describe a Managed Care Organization (MCO) in Family Care (FC))
COBRA	Consolidated Omnibus Budget Reconciliation Act of 1986
COP	Community Options Program
COP-W	Community Options Program-Waiver
CSP	Community Support Programs
CWIC	Community Work Incentive Counselor
CYSHCN	Children and Youth with Special Health Care Needs
DDB	Disability Determination Bureau
DHS	Department of Health Services
DNR	Do-Not-Resuscitate order
DPI	Department of Public Instruction
DVR	Division of Vocational Rehabilitation
DWD	Department of Workforce Development
FC	Family Care
FCP	Family Care Partnership
FPL	Federal Poverty Level
HCPOA	Health Care Power of Attorney
HIPAA	The Health Insurance Portability and Accountability Act
IDEA	Individuals with Disabilities Education Act
IEP	Individualized Education Program
IM	Income Maintenance (also referred to as Economic Support (ES))
IPE	Individual Plan for Employment
IRIS	Include, Respect, I Self-Direct
ISP	Individualized Service Plan
LEA	Local Education Agency
MA	Medical Assistance (also referred to as Medicaid and Title XIX or 19)
MAPP	Medical Assistance Purchase Plan
MCO	Managed Care Organization (see also CMO)
OC	Options Counselor (may also be referred to as an Enrollment Counselor)
ORCD	Office for Resource Center Development
PACE	Program of All-Inclusive Care for the Elderly





PASS	Plan to Achieve Self Support
SDS	Self-Directed Support(s)
SETT	Student / Environment / Task / Tool Process
SSA	Social Security Administration
SSDI	Social Security Disability Insurance
SSI	Supplemental Security Income
TIG	Transition Improvement Grant

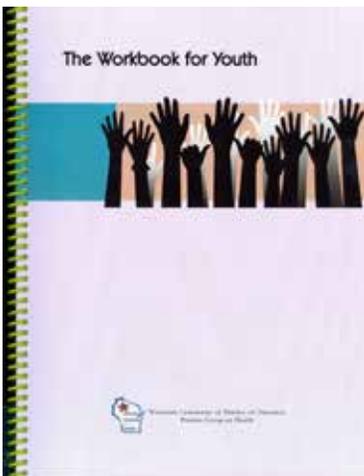


Youth Health Transition Publications



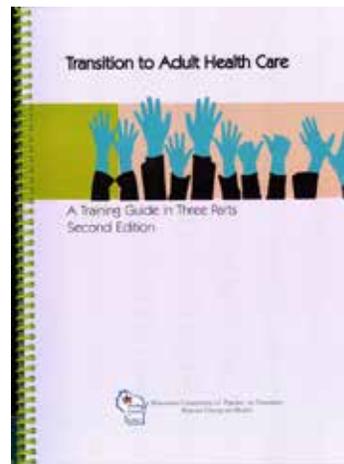
The Wisconsin Community on Transition Practice Group on Health has developed a set of health-related training materials that can be used with schools, health providers, families and directly with youth to help youth with disabilities learn to more effectively manage their health care concerns.

* The Workbook for Youth



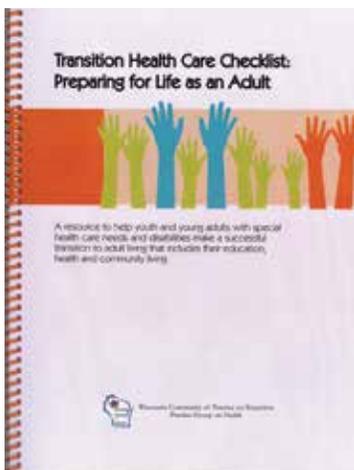
This content focuses on helping youth develop and practice the skills needed for managing their own health care, such as talking to their doctor and refilling prescriptions.

* Transition to Adult Health Care A Training Guide in Three Parts



This training guide explains how to conduct a health training and options for using the workbook and pocket guide. While the training is focused on preparing youth with special health care needs for adult life, the content is important for any young person.

Transition Health Care Checklist: Preparing for Life as an Adult



This booklet for youth preparing for the transition to adult life provides an overview of the knowledge, skills and actions that need to be addressed as part of transition for youth with special health care needs. It includes skills checklist and an overview of Wisconsin transition resources and supports.

My Health Pocket Guide



This portable pocket guide can help youth keep track of health care information. It is small enough to carry in a planner or calendar. Youth can use the tips and reminders as a guide when meeting with health providers.

* Available electronically at <http://www.waisman.wisc.edu/ucedd/all-products.htm>

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