

Build Your Bridge: Moving from Child to Adult Health Care

Parent Workbook



Dreaming Differently:
Planning the Transition to Adult Health Care

This Parent Workbook is designed to support the following two training activities:

Build Your Bridge: Moving from Child to Adult Health Care

Dreaming Differently: *Planning the Transition to Adult Health Care for Children with intellectual disabilities and/or complex medical needs*

This workbook will help you start thinking about your child's movement from child-centered to adult health care, and applies to all children who will turn 18. The tools provided will help you plan for health care transition. The information is important to consider even if not changing provider or clinic after age 18.

Write the name of the group that gave you this workbook in the lines below, for questions you may have about health care transition.

To view this guide online, check for updates, or learn more about the initiative, visit www.HealthTransitionWI.org.

To order copies of the workbook email the team at healthtransitionwi@waisman.wisc.edu.

Build Your Bridge: Moving from Child to Adult Health Care

Dreaming Differently:

Planning the Transition to Adult Health Care

Parent Workbook

Developed by:

Youth Health Transition Initiative

University Center for Excellence in Developmental Disabilities (UCEDD)

A Project of Wisconsin Health Transition Initiative and the Wisconsin Department of Health Services,
Division of Public Health Bureau of Community Health Promotion, Family Health Section,
Children and Youth with Special Health Care Needs Program.

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About Wisconsin Youth Health Transition Initiative

The Wisconsin Youth Health Transition Initiative (YHTI) promotes evidenced-based activities to advance health care practices, and support children and young adults and their families to transition from pediatric to adult health care systems. The YHTI encourages Wisconsin's youth, with and without special health care needs, to make individual choices to enhance their health and well-being.

The YHTI provides innovative health care transition tools, resources, and policies to support all children and young adults as they move to adult health care.

The YHTI works in collaboration with Wisconsin's network of Regional Centers for Children and Youth with Special Health Care Needs (CYSHCN). Regional Center contact information is at the end of this workbook.

For more information visit our website at HealthTransitionWI.org.

This workbook will provide different tools your family can use to assist you and your child in taking a more active role in their health care and planning for a successful transition.



Build Your Bridge: Moving from Child to Adult Health Care



Build Your Bridge: Moving from Child to Adult Health Care is a training to help guide families through the transition from child-centered to adult health care systems.

By the end of the training, participants will be able to:

- Define youth health care transition: what it is and why it is important;
- Identify activities in daily life for which transition occurs;
- Apply tools and resources to take an active role in the health care process;
- Start a healthcare transition action plan.



Dreaming Differently: Planning the Transition to Adult Health Care














Dreaming Differently: Planning the Transition to Adult Health Care. A training for families who are raising children with significant intellectual or developmental disabilities and medical complexity.

By the end of the training, participants will be able to:

- Review 3 steps related to a successful transition to adult health care;
- Identify the timeframe for transition activities and the planning process;
- Discuss 5 tools to use in moving to adult care;
- Prioritize the first action step to do following the presentation.



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Sample Transition Readiness Assessment for Youth

Please fill out this form to help us see what you already know about your health, how to use health care, and the areas you want to learn more about. If you need help with this form, please ask your parent/caregiver or doctor.

Preferred name

Legal name

Date of birth

Today's date

TRANSITION IMPORTANCE & CONFIDENCE *Please circle the number that best describes how you feel now.*

The transfer to adult health care usually takes place between the ages of 18 and 22.

How important is it to you to move to a doctor who cares for adults before age 22?

0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10
not _____ very

How confident do you feel about your ability to move to a doctor who cares for adults before age 22?

0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10
not _____ very

MY HEALTH & HEALTH CARE *Please check the answer that best applies now.*

NO

I WANT TO
LEARN

YES

I know how to ask questions when I do not understand what my doctor says.

☐☐☐

I know my family medical history.

☐☐☐

I see the doctor on my own during an appointment.

☐☐☐

I know where to get medical care when the doctor's office is closed.

☐☐☐

I carry important health information with me every day (e.g., insurance card, emergency contact information).

☐☐☐

I know that when I turn 18, I have full privacy in my health care.

☐☐☐

I know at least one other person who will support me with my health needs.

☐☐☐

I know how to find my doctor's phone number.

☐☐☐

I know how to make and cancel my own doctor appointments.

☐☐☐

I have a way to get to my doctor's office.

☐☐☐

I know how to get a summary of my medical information (e.g., online portal).

☐☐☐

I know how to fill out medical forms.

☐☐☐

I know how to get a referral if I need it.

☐☐☐

I know what health insurance I have.

☐☐☐

I know what I need to do to keep my health insurance.

☐☐☐

I talk with my parent/caregiver about the health care transition process.

☐☐☐

MY MEDICINES *If you do not take any medicines, please skip this section.*

I know my own medicines.

☐☐☐

I know when I need to take my medicines without someone telling me.

☐☐☐

I know how to refill my medicines if and when I need to.

☐☐☐

WHICH OF THE SKILLS LISTED ABOVE DO YOU MOST WANT TO WORK ON?

Build Your Bridge: Moving from Child to Adult Health Care



Transitioning Youth to an Adult Health Care Clinician
Six Core Elements of Health Care Transition™ 3.0

Sample Transition Readiness Assessment for Parents/Caregivers

Please fill out this form to help us see what your child already knows about their health and the areas you think they want to learn more about. After you complete the form, you can ask your child to share their answers from their completed form, and you can compare them. Your answers may be different. Your child's doctor will help you work on steps to increase your child's health care skills.

Youth name _____

Parent/Caregiver name _____

Youth date of birth _____

Today's date _____

TRANSITION IMPORTANCE & CONFIDENCE *Please circle the number that best describes how you feel now.*

The transfer to adult health care usually takes place between the ages of 18 and 22.

How important is it to your child to move to a doctor who cares for adults before age 22?

0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10
not _____ very

How confident do you feel about your child's ability to move to a doctor who cares for adults before age 22?

0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10
not _____ very

MY CHILD'S HEALTH & HEALTH CARE *Please check the answer that best applies now.*

NO

THEY WANT
TO LEARN

YES

My child knows how to ask questions when they do not understand what their doctor says.

☐☐☐

My child knows our family medical history.

☐☐☐

My child sees the doctor on their own during an appointment.

☐☐☐

My child knows where to get medical care when the doctor's office is closed.

☐☐☐

My child carries important health information with them every day (e.g., insurance card, emergency contact information).

☐☐☐

My child knows that when they turn 18, they have full privacy in their health care.

☐☐☐

My child knows at least one other person who will support them with their health needs.

☐☐☐

My child knows how to find their doctor's phone number.

☐☐☐

My child knows how to make and cancel their own doctor appointments.

☐☐☐

My child has a way to get to their doctor's office.

☐☐☐

My child knows how to get a summary of their medical information (e.g., online portal).

☐☐☐

My child knows how to fill out medical forms.

☐☐☐

My child knows how to get a referral if they need it.

☐☐☐

My child knows what health insurance they have.

☐☐☐

My child knows what they need to do to keep their health insurance.

☐☐☐

My child and I talk about the health care transition process.

☐☐☐

MY CHILD'S MEDICINES *If your child does not take any medicines, please skip this section.*

My child knows their own medicines.

☐☐☐

My child knows when they need to take their medicines without someone telling them.

☐☐☐

My child knows how to refill their medicines if and when they need to.

☐☐☐

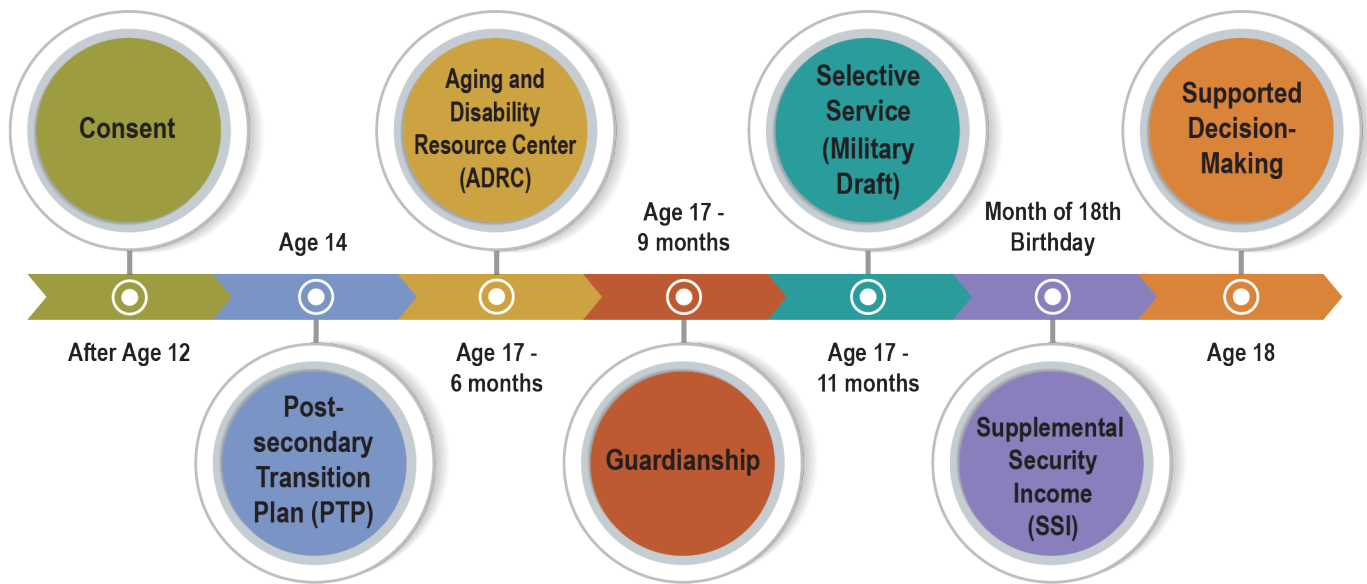
WHICH OF THE SKILLS LISTED ABOVE DOES YOUR CHILD MOST WANT TO WORK ON?



Build Your Bridge: Moving from Child to Adult Health Care

Transitioning Youth to an Adult Health Care Clinician
Six Core Elements of Health Care Transition™ 3.0

Transition in WI: Brief Timeline



This timeline represents the sequence of events and recommended ages for transition to adulthood. It includes all the areas where your child will transition: school, privacy and decision-making, health insurance, and health care. It's important to keep these in mind as your child moves through the transition years of 12-18.

Ages 12-14 – All systems have different policies and may even require consent for parents to see the medical records, starting as early as age 12. You should discuss this with your primary doctor, particularly if you have on-line access to records, to continue access to your child's health record.

Age 14 "PTP" – stands for Postsecondary Transition Plan that your school will start to create with your input at age 14, around 8th grade.

Age 17 & 9 months – Contact your local Aging and Disability Resource Center or ADRC. It is the gateway to applying for long term care supports when your child is almost 18.

Age 17 & 9 months – If you choose guardianship, you can apply when your child is at age 17 and 9 months.

Age 17-18 – The process of developing a Supported Decision-Making agreement needs to start early. Think of any way your child can learn to make a decision and of people (supporters) who will be willing to help out with decision-making now and in the future.

Month of the 18th birthday – Officially apply for Supplemental Security Income or SSI. Start preparing to apply at age 17; you can submit an application during the month of your child's 18th birthday.

Selective service is the registration for military service. Every male is required to register or get a waiver.

Adult Provider(s)



Health care transition involves much more than finding a primary doctor.

If your child's primary care provider is in family medicine, you may think that transition does not occur. Keep in mind that transition involves much more than finding a new primary doctor.

When choosing a new provider, you can ask friends or your doctor for suggestions. Many specialists only work with children or adults. There may be specialists currently on your child's medical team who also need to be considered in a transfer to adult care.

There are also pediatric dentists, who will only see children and young adults up to a certain age. For some, this can be a big change and it may take multiple visits before your child feels comfortable.

Keep in mind that building a relationship with a new provider is going to take time.

What if my child's doctor says we can stay with them?

That may be okay for regular visits, but if your child requires surgery, has an emergency, or needs to be admitted to the hospital, they may not be able to see their regular doctor. When a child turns 18 years old, they will be treated as an adult. If you plan to stay with your child's doctor, talk about how you will plan for these unexpected situations.

Adult Provider(s)



Next steps: Identify an adult provider who will care for your adult child.

Who will help me to identify a new doctor, dentist or specialist?

- Ask current medical provider for recommendations.
- Check with family and friends.
- Search online, and read the reviews posted by others.
- See if the clinic or health system supports people with similar conditions.
- Ask adults who have a similar condition.
- Call your health insurance company or look through your health plan coverage booklet.

Who are the current providers:

Name	Specialty	Do they see adult patients?

Create a list of possible future providers and contact information.

Name	Specialty	Contact Information	Are they covered by your insurance?

Reminder: Talk with my child's doctor about a transition plan.

Bonus Material:

Check out the 'Bonus Material' page for more information on this topic.

Decisions



Healthy Living

Healthy living starts with healthy behaviors, so it is important to talk with your child about making healthy choices. Here are some key elements to consider to encourage a healthy lifestyle:

Diet: Eat smart by avoiding unhealthy foods; be sure to include vegetables and fruits.

Physical Health: Be active, exercise, and get a good night's sleep (8 hours/night).

Mental Health: Manage stress by doing some form of stress release every day.

Hygiene: Brush teeth for two minutes twice a day and practice good skin care and proper washing.

Sexual Health: Make sex a choice between two consenting individuals, and always carry a condom.

Safe Behaviors:

Hearing – protect ears from noise louder than a lawn mower.

Helmet – wear one when biking, rollerblading, skiing, etc.

Internet Safety – know that a post is saved forever.

Alcohol use: The best advice, don't drink. If you drink, eat first, and don't let anyone else pour or top off your drink.

Avoid Toxins: Cigarettes, vapors, huffing, alcohol are all forms of toxins that are harmful.

Driving: Keep your phone and other devices out of your hands, and wear your seat belt.

Interests: Have a passion, and do it as often as you can.

Making simple decisions gives children the confidence to make bigger decisions.

Five steps to help your child make good decisions:

1. Explore the Details
2. Evaluate the Consequences
3. Trust Your Judgment
4. Make the Best Decision
5. Recognize You Can Change Course

– Gary and Joy Lundberg

Decisions



Privacy and Health Information

As your adult child gets older, their rights to privacy change.

In Wisconsin, parents' access to medical information for children ages 12 to 17 is limited. Although they are still considered children, and referred to as minors, they have the right to consent to certain health care services without their parents' knowledge or consent.

Clinics and health care systems will start to recognize your child's growing independence, and at each doctor visit, your child might need to sign a HIPAA authorization in order for you to continue to have access to their medical information. Some clinics may also remove your access to view your child's health information online. Different forms allow access to different things relating to your child's health and transition ages.

Take time to read the forms, and ask your clinic if you have questions about what they mean when it comes to viewing, accessing, and making decisions for your child.

3 Things You Can Do Right Now

1. Develop a good relationship with your child's providers.
2. Know your child's legal rights and the ages when they change.
3. Encourage taking responsibility for health care decisions.

Confused? Don't worry, you're not alone.
Our partners at Wisconsin PATCH can help!

Providers And Teens Communicating for Health (PATCH)

has resources for teens, parents, and providers about a variety of health topics, from mental health to confidentiality and much more!

wi.patch.org

Decisions



Definitions

HIPAA authorization (Release of Information): The Health Insurance Portability Act of 1996 (HIPAA) authorization is like a permission slip. It permits healthcare providers to disclose health information to anyone your child specifies. It sets boundaries on the use and release of health records to protect privacy and is essential to keeping trust between a doctor and the patient. Signing this agreement does not allow you to make medical decisions for your child.

Note: Privacy permissions can be revoked verbally by the patient at any time.

Medical power of attorney (MPOA): In signing an MPOA, your young adult child will appoint an “agent” to make medical decisions on their behalf in case they are incapacitated and cannot make such decisions for themselves. Each state has different laws governing MPOAs. An MPOA is a legal document that is highly recommended for every adult.

Durable power of attorney (DPOA): As an additional step, young adult children might consider appointing a durable power of attorney, enabling a parent or other designated agent to take care of financial business on the adult child’s behalf.

Note: MPOA and DPOA do not go into effect unless and until the person is incapacitated and unable to make decisions.

Additional questions to consider...

- What decisions are you currently making for your child that you could allow them to make for themselves?
- How can you make decisions more accessible to your child (offering options to choose from, using pictures)?
- What support will your child need to make legal decisions?

Decisions



Definitions

Guardianship: a person or agency chosen or appointed by a court to make legal decisions for another person, who is unable to make those decisions on their own. Guardianship can be applied for at age 17 years and 9 months.

Self-Advocate: a person who actively promotes their wants and needs that lead to achieving a goal.

Supported Decision-Making: a process used to have friends, family members and professionals help a person understand situations and choices they face, so they may make their own decisions.

Practice: Every day encourage your child to make decisions, for example, giving 2 choices of snacks.

For more information about **Supported Decision-Making** and alternatives to guardianship, visit Family Voices of Wisconsin at <https://familyvoiceswi.org/> and the Wisconsin Board for People with Developmental Disabilities at <https://wi-bpdd.org/>

For more information about **Guardianship**, visit the Greater WI Agency on Aging Resources, Inc. (GWAAR) at <http://gwaar.supranet.net/wi-guardianship-support-center.html>

Bonus Material:

Check out the 'Bonus Material' page for more information on this topic.

Health Insurance



Health insurance can be complicated, but there are important things about health insurance your child needs to know as they get older.

When my young adult child becomes an adult, how do they get health insurance?

As a parent you can help your young adult child consider their particular options as they reach the age of 18. Some may continue on their parents' plan, while others may need to apply for Medicaid through BadgerCare Plus or Supplemental Security Income (SSI) eligibility. Still others may get coverage through a job.

Practice: Your child can practice giving their insurance card to the receptionist when checking in.

Definitions:

Co-pay: A fixed amount you pay out of pocket when you get some health services.

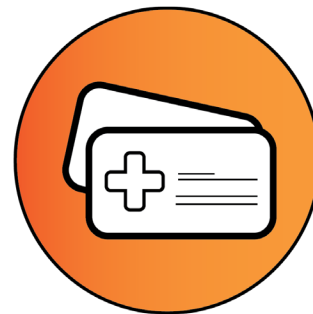
Preventative: Services that are typically covered in full under health insurance such as shots and screening tests like blood pressure or cholesterol screenings.
Note: These services are only covered when delivered by a doctor in your health care plan's network.

Co-Insurance: A percentage of the cost of health services paid by the patient.

Deductible: The amount you pay per year (per person or per family) before your health insurance covers most or all of the costs.

Premium: The cost paid up-front for health insurance. This is typically a monthly fee that is paid by an individual in order to be covered by health insurance.

Health Insurance



Should my child carry an insurance card?

Yes, everyone should carry their own insurance cards and know how to contact member services. This phone number is often found on the back of the card.

Additional questions to consider ...

Is my coverage through private insurance or public benefits?

Note about public benefits: As a child reaches their 18th birthday, they will need to reapply for public assistance. The eligibility requirements change from what is considered for children versus adults.

What does it cover? What does it cost?

What services are included?

Which doctors can I see? Which clinics or hospitals can I use?

What type of health insurance is best for me?

Note: Your child may qualify for more than one health insurance and you will also need to think about coverage for other services such as dental and vision.

Will my insurance change at 18?

Are public benefits appropriate for me?

Bonus Material:

Check out the 'Bonus Material' page for more information on this topic.



Emergency Contacts

Entering Emergency Contact Information in Your Phone

Since phones are continually changing, and everyone's is different, its best to go to the website for up to date instructions. These instructions are examples of how easy it is to use the Health app.

It's always good to know who to call in case of an emergency.

iPhone: Apple instructions: <https://support.apple.com/en-us/HT207021>

1. Open Health and tap Medical ID > Get Started.
2. Enter emergency contacts and other health information like birth date, height, and blood type. Enter only what you are comfortable having others see!
3. Turn on Show When Locked to make your Medical ID available from the Lock screen.
4. When finished, tap Done.

Android: Android instructions: <https://support.google.com/android/answer/9319337?hl=en>

1. Open Health and tap Medical ID > Get Started.
2. Enter emergency contacts and other health information like birth date, height, and blood type. Enter only what you are comfortable having others see!
3. Turn on Show When Locked to make your Medical ID available from the Lock screen.
4. When finished, tap Done.

Practice: Who you gonna call?

Examples:

- Wake up with an upset stomach?
- Lunch with friends and now have a rash?
- A little dizzy after standing up quickly?
- Fainting and falling down?
- Big cut that won't stop bleeding?
- Temperature of 104°F?



Emergency Contacts

Questions to consider for your child's action plan:

- Who will be the emergency contact(s)?
- How will they share this information with others?

How will my child know who they can call in an emergency?

- A list in their backpack?
- Emergency alert bracelet?
- In their phone?

Important Names & Numbers

Name	Phone Number
Name	Phone Number
Name	Phone Number
Name	Phone Number
Name	Phone Number
Name	Phone Number
Name	Phone Number

Appointments



It's best to have your child visit a new doctor before they are sick.

Your child should begin to learn how to make appointments to see new or existing doctors on their own. This is a skill you can practice. Avoid surprises. When you call for an appointment, check that the practice takes your health insurance.

Practice: Use the script below to practice.



Hello, my name is Mabel and I would like to schedule a visit with Dr. Webster. I have XYZ Insurance.

If you typically see this doctor or you are sure they accept your insurance, you may not need to tell them your insurance.

Okay, we accept that insurance. What is your full name and birth date?



Mabel Table, June 15, 2001.

Dr. Webster's next appointment is in two weeks, on Monday at 2 pm.



I have school until 3 pm, is there anything later?

Yes, our latest appointment is 4 pm, and that would also be in two weeks but on a Wednesday.



Yes, that will work for me.

Would you like us to send you a reminder card in the mail?



No, thank you. I will put the appointment on my phone calendar.

Appointments



I can encourage my young adult child's independence at appointments.

Things to discuss before calling to schedule an appointment:

- Does this doctor take my insurance?
- What number do I call to make an appointment?
- What type of appointment do I need?
- When am I available?
- How do I get to the appointment?
- How do I remember to go?

Things to discuss with your child:

- Does my healthcare system allow appointments to be made online?
- Discuss if I need a same day appointment.
- A same day appointment may mean I see another doctor.
- If I need another appointment, how do I schedule it?

Things to encourage your child to do at the appointment:

- Prepare for the appointment by creating a list of questions.
- Check in for the appointment.
- Try completing paperwork alone or complete it together.
- Have your child sit next to the doctor.
- Encourage time alone with the doctor.
- Take notes during the appointment, and review with your child after the visit.

Medications




The pharmacist can be an important member of the medical team. Have your child get to know the pharmacist.

Things you can do to encourage independence in safe medication management:

- Meet the pharmacist.
- Practice reading a medication label. Use the example provided below.
- Discuss how to fill a prescription.
- Discuss how to refill a prescription. Encourage your child to practice requesting a refill and be close by in case they have questions.

Practice: An example of a prescription label.

FOGHORN LEGHORN 1212 N ROOSTER RD, OREGON, WI 53575		11/09/20	Warning: Do not use if you are pregnant, suspect that you are pregnant, or while breastfeeding. Consult your doctor or pharmacist. Take this medication ½ hour before a meal. Read label carefully for how many times to take each day.  NDC: 00093-0670-05
TAKE ONE TABLET TWO TIMES A DAY			
GEMFIBROZIL 600 MG TABLET			
RX: 6000254-99 (608) 241-9638	QTY: 60 REFILLS: 4 UNTIL 5/09/21 . A YOUNG USE BY: 11/09/21		
MFG: TEVA USA			

Medications



Actions I can take to encourage my young adult child to manage medications safely:

Discuss each medication.

- Explain the purpose of each medication.
- Label the bottles with the reason for taking the medication.
- Talk about the difference between medications given by a doctor (prescribed) and those without a prescription (over the counter).

If your young adult child uses medical equipment or supplies, use the same discussion tips above to discuss use and refills.

Discuss names of medications. Teach how to:

- Recognize the name of the medication by seeing it or hearing it pronounced.
- Know what the medication looks or feels like.
- Carry a list in a wallet or phone.

Discuss the dosage and how to take it.

- Know how much (dosage) of the medication is needed and how it is given (orally, inhaled, swallowed, injected).

Discuss allergies and drug interactions.

- Carry a list of allergies or have them listed on their phone.

Discuss Side Effects.

- Create a chart or medication diary.

Encourage independence by remembering to take medication.

- Pill sorters
- Calendars
- Apps (Medisafe)

Bonus Material:

Check out the 'Bonus Material' page for more information on this topic.

Health Summary



Health Summary or Shared Plan of Care (SPoC)

A health summary is handy to have when children change doctors.

Create a health summary using a notebook or binder.

A health summary includes your child's medical information, conditions, diagnoses, surgeries, allergies, medications, medical equipment, immunizations, and personal as well as family medical history.

Many health systems now offer this information electronically, but if your child is moving to a doctor in another health system, that doctor may not be able to access the information.

You can create your child's health summary using a notebook or binder from any office supply store. Use the following labels at the top of each page and then fill out the pages with information specific to your child.

Possible headings:

- Basic information (name, date of birth, address)
- Health insurance information
- Conditions
- Surgeries
- Allergies
- Medications
- Medical Equipment
- Immunizations
- Family health history

Print a copy of the health summary and share it with new doctors.

Health Summary



Consider including other things that are unique about your child's needs.

This workbook offers several common areas that should be included in a health summary. This will help start your child's health summary. If you do not see a topic that is important for their needs, you can always add more pages.

Additional areas you may want to consider:

Medical Records:

- Does your child receive care from more than one clinic?
- Are the clinics part of the same medical record system?
- If not, you may want to ask for hard copies of your visits and keep them in a folder when you go from doctor to doctor.

Health Goals for you to work on with your child:

- Take more responsibility for their own health care.
- Start with where they are now and take small steps.
- Build a good relationship with their doctor(s) based on good communication.
- Discuss goals with the doctor and plan how together they can meet these goals.

Things that must happen in the next 6 to 12 months.

The transfer of care for your young adult child will take time; however, there are situations where this process might leave them temporarily without access to necessary health care services. Create a list of services, procedures, or access to health care that they may need over the next 6 to 12 months. Use this list to start a discussion with the doctor about critical needs for your child, and decide who will take care of these needs during the transition process. This is sometimes called a "summative problem list" by doctors, or a Health Summary.

Health Summary



Mental Health

Like a physical health condition, recognizing and seeking treatment for a mental health condition early on leads to better outcomes.

These feelings and behaviors include:

- Eating or sleeping too much or too little;
- Avoiding people and usual activities;
- Having low or no energy;
- Feeling numb or like nothing matters;
- Feeling helpless or hopeless;
- Feeling unusually confused, forgetful, on edge, angry, upset, worried, or scared;
- Experiencing severe mood swings that cause problems in relationships;
- Hearing voices or believing things that are not true;
- Thinking of harming one's self or others.

Discuss concerns with your child and their primary care doctor, another health professional, or other trusted resource in the community.

Be Involved: It is important to be actively involved in your child's life. Get to know their friends and what they do together. Be aware of how they are performing in school.

Shared Plan of Care (SPoC)

A Shared Plan of Care is a form filled out by parents, youth, and the health care provider. It is meant to make sure that everyone caring for your child knows about medical conditions, and that next steps in care are outlined. There are many templates to choose from. You will find one example at this link. <https://www.chawisconsin.org/download/shared-plan-of-care-summary/>

There are three essential elements to a Shared Plan of Care:

1. Medical Summary
2. Family Strengths and Preferences
3. Negotiated Actions

Bonus Material:

Check out the 'Bonus Material' page for more information on this topic.

About Me



Take some time and decide how you would describe your young adult child to a new doctor.

For parents/caregivers, things to include:

- How your young adult child learns.
- What are their likes, dislikes, and hobbies.
- Who is important to them?
- What makes your child feel uncomfortable and how can it be made better?
- What health condition(s) do they have?
- How comfortable are you with their making decisions?
- Can your child describe what hurts?
- Can they identify symptoms and when they might need to see a doctor?

How much information to share?

It is important to discuss sharing personal information. It is important to share all health information with the doctor, and at the same time, talk about privacy with your child and how much information they should share with others.

Sharing personal information depends on trust. A good place to start:

- Other family members
- Teachers
- Friends
- Colleagues (if appropriate)
- Employers (if appropriate)

How will my child introduce themselves to new people?

Examples: verbal, video, picture book

Bonus Material:

Check out the 'Bonus Material' page for more information on this topic.

Bonus Material:



Adult Provider(s)

Finding an Adult Provider -

<https://illinoisap.org/wp-content/uploads/2020/01/Finding-Adult-Providers.pdf>

Health Information and Your Rights - <https://www.healthit.gov/access>



Decisions

Teaching Decision-Making Starting at a Young Age – Fostering Self-Determination Among Children and Youth with Disabilities

Ideas for Parents for Parents - <https://www.saintlouispartners.org/wp-content/uploads/2018/02/FosteringSelfDetermination.pdf>

Supported Decision Making from our partners at Family Voices of Wisconsin - familyvoiceswi.org

Guardianship and Health Care Power of Attorney from the Aging and Disability Resource Center (ADRCs) - dhs.wisconsin.gov/adrc

Greater Wisconsin Agency on Aging Resources, Inc. (GWAAR) - gwaar.org/wi-guardianship-support-center.html

Guardianship and Alternatives to Guardianship
Wisconsin Board for People with Developmental Disabilities (WBPDD) - wi-bpdd.org

Providers and Teens Communicating for Health (PATCH) - wipatch.org



Health Insurance

Marketplace Insurance - Healthcare.gov

Are Public Benefits right for you? - Access.Wisconsin.gov,
click on, “Am I Eligible?”

Bonus Material:



Medications

ABC for Health - 608.261.6939 or 1.800.585.4222 or safetyweb.org

Video link - <https://youtu.be/eUuAapOGDSM>

Medisafe Medication Reminder App; download from your device's App Store.

Teaching Kids About Using Medicine Safely

Video link - <https://youtu.be/gHv7KWB9RuI>



Health Summary

Wisconsin Board for People with Developmental Disabilities (WBPDD) Health Care Kit for individuals with developmental and intellectual disabilities (I/DD) -

<https://wi-bpdd.org/index.php/2017/08/15/bpdd-health-care-kit-available/>

Condition specific guides: The American College of Physicians created condition specific guides. - bit.ly/1Vhg3Hr

Mental Health - 2 page flyer -

mentalhealthjustice.net/blog/2015/8/25/get-on-the-road-to-living-well

National Collaborative on Workforce and Disability. A Young Person's Guide to Health Care Transition -

<http://www.ncwd-youth.info/publications/a-young-persons-guide-to-health-care-transition/>

WI Medical Home, Advancing Family-Centered Care Coordination using a Shared Plan of Care -

<https://www.chawisconsin.org/download/shared-plan-of-care-summary/>



About Me

National Institute of Children's Health Quality, A digital template for a Shared Plan of Care -

<https://www.nichq.org/resource/nichqs-care-plan-template>

Center for Patient Partnerships - patientpartnerships.org

Other Resources:

WI Youth Health Transition Initiative - healthtransitionwi.org

Got Transition - GotTransition.org

Wisconsin Medical Home Initiative -
<https://www.chawisconsin.org/initiatives/medical-home/wisconsin-medical-home-initiative/>

Before Age 18 - beforeage18.org

WI FACETS - <https://wifacets.org/programs/local-projects>

Parent 2 Parent of Wisconsin - p2pwi.org

Becoming an Adult: Taking Responsibility for Your Medical Care -
Video Link: <https://youtu.be/cjXurYrFMZM>

Transitioning from Pediatric to Adult Care -
Video Link: https://youtu.be/f_yMwg66-w0

Selective Service System -
<https://www.sss.gov/register/who-needs-to-register/>

Transition Action Plan



Child's Name: _____

Current Age: _____

Date: _____



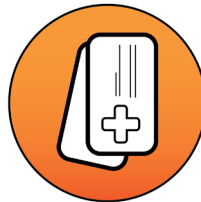

Next Steps:

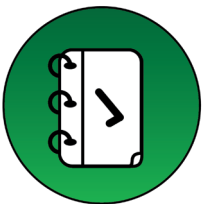


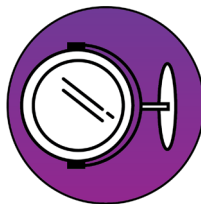
Here is a summary of the tools discussed in this workbook as well as a list of additional questions for you to consider as you take the next steps in your child's health care transition.

Transition Action Plan

Name _____ Age: _____ Date _____



Tool	Page#	Next Step(s)	Who is involved?
 Adult Provider(s)	4-5		
 Decisions	6-9		
 Health Insurance	10-11		
 Emergency Contact	12-13		

Tool	Page	Next Step(s)	Who is involved?
 <p>Appointments</p>	14-15		
 <p>Medications</p>	16-17		
 <p>Health Summary</p>	18-20		
 <p>About Me</p>	21		

CYSHCN Regional Center

