Bridging the Gap

Bridging the Gap:
Transition from Pediatric to Adult Health Care

Southern Regional Center
Children and Youth with
Special Health Care Needs

HEALTH TRANSITION WISCONSIN
SUPPORTING YOUTH TO ADULT HEALTHCARE

WAISMAN CENTER
UNIVERSITY OF WISCONSIN-MADISON
University Center for Excellence in Developmental Disabilities

Presenters

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Parent
Youth Health Transition Initiative
Children and Youth With Special Health Care Needs
Southern Regional Center Director

Hunter Markle

Young Adult

Who we are

Primary Network in Wisconsin

Family Voices of Wisconsin

PARENT 2 PARENT WISCONSIN

WISCONSIN Medical Home
Children's Health Alliance of Wisconsin

Wisconsin Title V Children and Youth with Special Health Care Needs Program

WELL BADGER RESOURCE CENTER

ABC FOR HEALTH Since 1994

HEALTH TRANSITION WISCONSIN
SUPPORTING YOUTH TO ADULT HEALTHCARE

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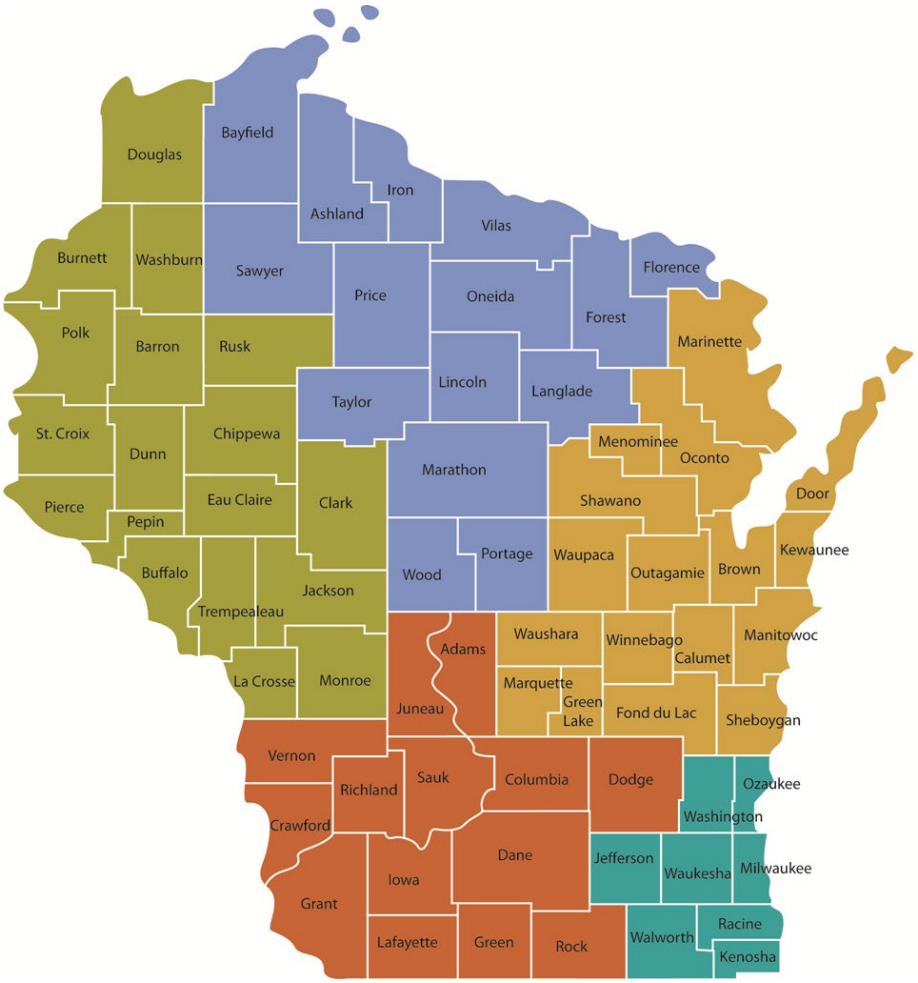
Regional Centers
Wisconsin



Statewide Initiative

HEALTH TRANSITION WISCONSIN

SUPPORTING YOUTH TO ADULT HEALTHCARE

Youth Health Transition Initiative
YHTI

Statewide Initiative

HEALTH TRANSITION WISCONSIN

SUPPORTING YOUTH TO ADULT HEALTHCARE

Purpose

- Ensure that "high-quality, developmentally appropriate, health care services are available in an uninterrupted manner as the person moves from adolescence to adulthood"

Process

- Transition starts in early adolescence
- Transfers of care between 18 and 22 years of age

American Academy of Pediatrics, American Academy of Family Physicians, & American College of Physicians, 2011, p. 182; Human Resources & Services Administration [HRSA], 2016

WI Youth Health Transition Efforts

- Supports health care providers and organizations moving transition efforts forward within systems
- Facilitates *Transition Learning Community*, a virtual statewide network sharing best practices around transition
- *Health Transition Wisconsin* website and community outreach
- Disseminates health transition resources to partners through trainings, exhibits and community partnerships

Where We're Going

1. What is Health Care Transition anyway?
2. Introduce the Transition Readiness Assessment for Parents & Youth
3. Introduce the Eight Tools for Health Care Transition
4. Discuss way to help youth talk about their own health and advocate for their own health.

Personal Story Time

What is Health Care Transition?

Health care transition is the process of changing from a pediatric to an adult model of health care.

Got Transition website

https://www.gottransition.org/providers/index.cfm; accessed 2/5/19

Who needs to think about transition?

Teens who are, or will be turning 18, and their families/supports.

Especially if identified with a disability or health care need.

Why is health so important?

Increased independence.

Success in day to day life.

Opportunity for secondary education.

Working.

When do other transitions occur?

Age 16	**Drive**	
Age 18	**Vote**	**Adult**
Age 21	**Drink - responsibly**	

When do other transitions occur?

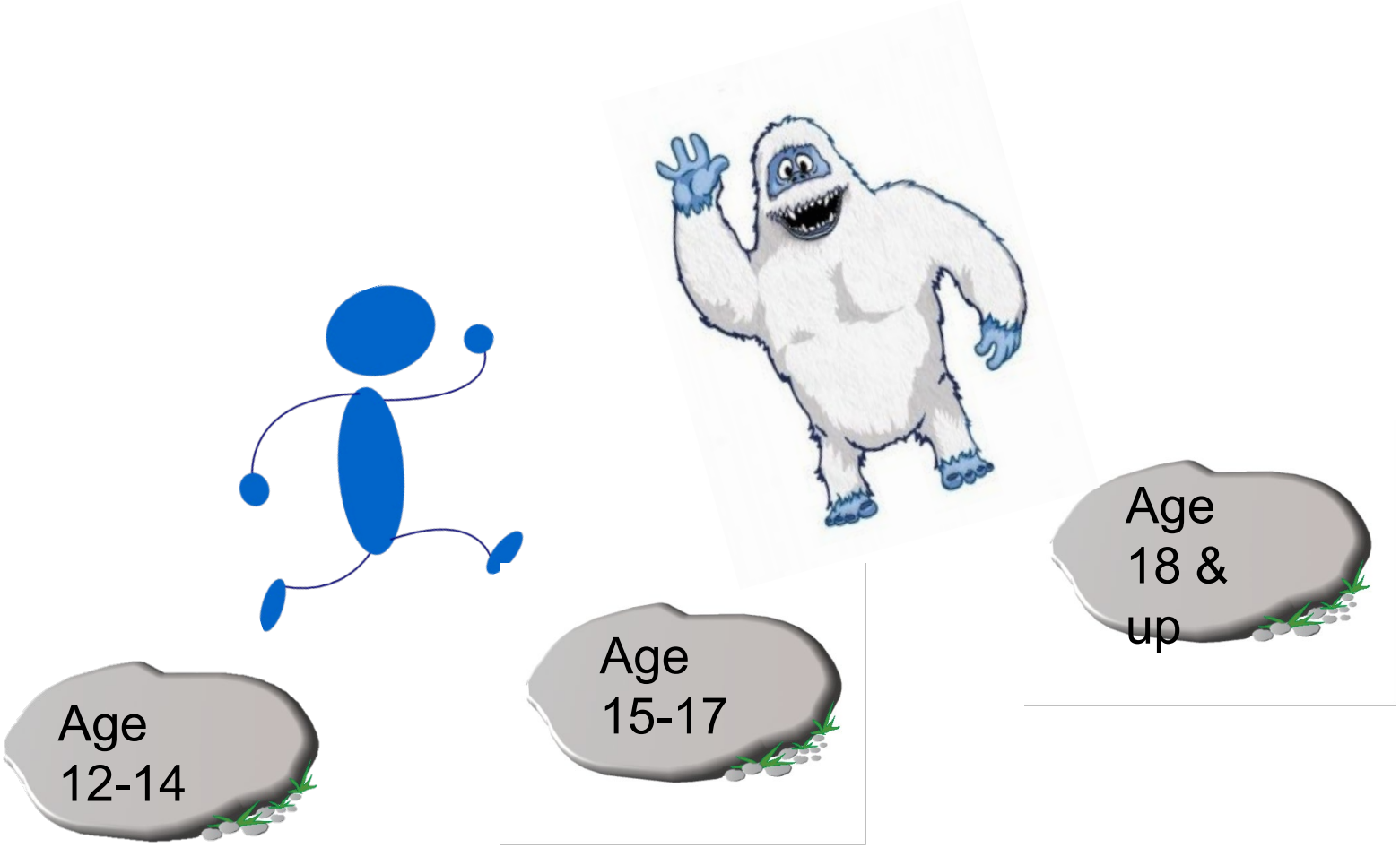
Age 16 — **Drive**

Age 18 — **Vote**

Age 21 — **Drink - responsibly**

ADULT

Stay a Step Ahead



Tools & Resources

Tools

1. Readiness Assessment
2. Eight tools of Transition

Readiness Assessment

What do you already know about your health?

Transition Readiness Assessment (TRA)

This health care transition readiness assessment is intended for students and their family/caregivers to compete as part of IEP transition planning meetings.

https://www.gottransition.org/resource/?tra-iep-english

https://www.gottransition.org/resource/?tra-iep-spanish

Pediatric to Adult Health Care Transition Tool | **Health Care Transition Readiness Assessment** *for Students*

This health care transition readiness assessment is intended for students and their family/caregivers to compete as part of IEP transition planning meetings. If a student is unable to fill out this form, the student can complete it with the help of their family/caregiver.

Directions: Please check the box next to the answer that best applies to you right now. This helps us see what you already know about your health and using health care and areas that you need to learn more about.

Student Name: Student Date of Birth:

Completed By: Date Completed:

Personal Care *(related to dressing, eating, bathing, and moving)*	**Use of Communication Supports**
☐ I am able to care for all my needs	☐ Text-to-speech technology
☐ I need a little bit of help to care for my needs	☐ Assistive Listening Systems
☐ I need a lot of help to care for my needs	☐ ASL/Interpretation technology
☐ I need help to care for all my needs	☐ Other technology:
	☐ I do not use communication supports

Transition Importance & Confidence *On a scale of 0 to 10, please circle the number that best describes how you feel right now.*
**The transition to a doctor who cares for adults usually occurs between ages 18-22.*

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

0 (not)	1	2	3	4	5 (neutral)	6	7	8	9	10 (very)

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

0 (not)	1	2	3	4	5 (neutral)	6	7	8	9	10 (very)

My Health *Please check the box that applies to you right now.*	**Yes**	**I want to learn**	**No**
I can name my learning differences, disability, medical, or mental health diagnosis (e.g. diabetes, depression).	☐	☐	☐
I can name 2-3 people who can help me with my learning differences, disability, medical, or mental health needs in an emergency.	☐	☐	☐
Before a doctor's visit, I prepare questions to ask.	☐	☐	☐
I know to ask the doctor's office for accommodations, if needed.	☐	☐	☐
I have a way to get to my doctor's office.	☐	☐	☐
I know the name(s) of my doctor(s).	☐	☐	☐
I know or I can find my doctor's phone number.	☐	☐	☐
I know how to make my doctor's appointments.	☐	☐	☐
I carry my health information with me every day (e.g. insurance card, emergency phone numbers).	☐	☐	☐
I know my food allergies.	☐	☐	☐

My Medicines *Please check the box that applies to you right now.*	**Yes**	**I want to learn**	**No**
I know the name of the medicines I take.	☐	☐	☐
I know the amount of the medicines I take.	☐	☐	☐
I know when I need to take my medicines.	☐	☐	☐
I know how to read and follow the direction labels on my medicines.	☐	☐	☐
I know what to do when I run out of my medicines.	☐	☐	☐
I know my medicine allergies.	☐	☐	☐

The National Alliance To Advance Adolescent Health

got transition.

Sample Goals for the HCT RA

HCT Readiness Assessment Item	*Sample Goal*
I can name my learning differences, disability, medical, or mental health diagnosis (e.g. diabetes, depression).	By the end of the IEP cycle, student will say aloud and/or spell out and/or enter into their cell phone the name(s) of their medical or mental health diagnosis(es), with __% accuracy.
I can name 2-3 people who can help with my learning differences, disability, medical, or mental health needs in an emergency.	By the end of the IEP cycle, student will input their emergency contacts' information on their phone and name and identify the contacts in their phone when asked, with __% accuracy
Before a doctor's visit, I prepare questions to ask.	By the end of the IEP cycle, student will prepare and practice asking a few questions to their doctor before their next appointment, with __% accuracy.

Readiness Assessment

THE SIX CORE ELEMENTS OF HEALTH CARE TRANSITION™ 3.0

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 can explain my health needs to others.	☐	☐	☐
I know how to ask questions when I do not understand what my doctor says.	☐	☐	☐
I know my allergies to medicines.	☐	☐	☐
I know my family medical history.	☐	☐	☐
I talk to the doctor instead of my parent/caregiver talking for me.	☐	☐	☐
I see the doctor on my own during an appointment.	☐	☐	☐
I know when and how to get emergency care.	☐	☐	☐
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?

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Eight Health Tools

Health Transition Wisconsin

Supporting Youth to Adult Health Care Transition

https://healthtransitionwi.org/

https://healthtransitionwi.org/youth-families/

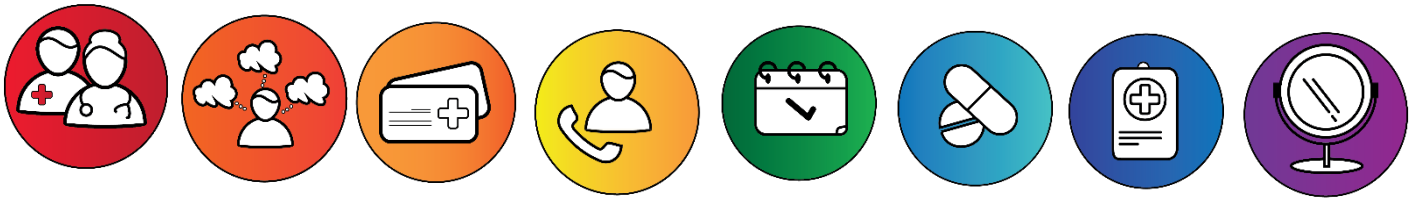
Step-by-Step

Check out these additional resources to take charge of your health care!

- Resources
- Build Your Bridge Workbook

Eight Health Tools

- Adult Providers
- Decisions
- Health Insurance
- Emergency Contacts
- Appointments
- Medications
- Health Summary
- About Me



Helpful in Variety of Settings

- Health care management and clinics
- Employment
- Independent Living
- High School / Post-secondary settings
- Completion of Post-Secondary Transition Plan
- Self-advocacy

Health and the PTP

Transition Improvement Grant (TIG)

https://www.witig.org/

Yes, there is an app for that!

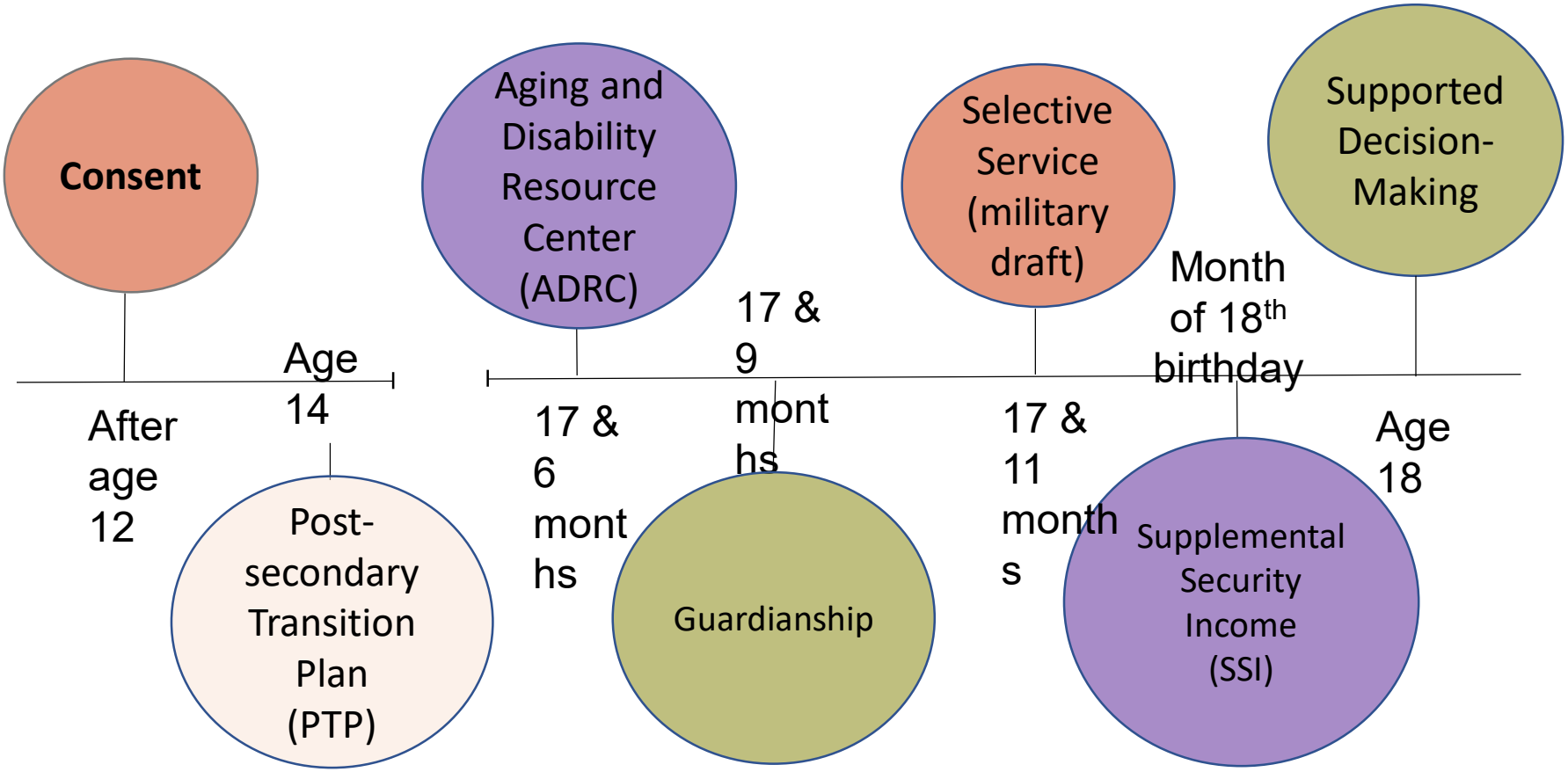
https://www.witig.org/witransition-app.html

www.witransition.com

Self-Advocacy

- Advocating for yourself in an effective manner- at school, work, or with those who are perceived as having power over you, shifts the dynamics of those relationships
- Self-advocacy also means that you get to choose when to pick your battles
- Self-advocacy can be a great source of self-care
- Learn more at: https://www.pacer.org/transition/learning-center/health/building-self-advocacy.asp

Transition in WI: Brief Timeline



Health Care Transition Timeline

RECOMMENDED HEALTH CARE TRANSITION TIMELINE

Age 12	Age 14	Age 16	Age 18	Age 18-22	Age 23-26
Make youth and family aware of transition policy	Initiate health care transition planning	Prepare youth and parents for adult model of care and discuss transfer	Transition to adult model of care	Transfer care to adult medical home and/or specialists with transfer package	Integrate young adults into adult care

https://www.gottransition.org/six-core-elements/

Final Recommendations from Parents

- Make a plan
- Record everything – keep a notebook
- Break the project into smaller tasks so it’s more manageable and less overwhelming
- Don’t be surprised if things do take longer than you expect.

Final Recommendations from Parents

- Ask questions of others involved in your child's life and health care
- Get to know other parents who are having a similar experience

Be kind and gentle with yourself

Next Steps

- Have students complete readiness assessment
- Start conversations
- Visit the Health Transition WI website and download the workbook
- Ask you IEP team to incorporate Health Care into Transition Planning

Next Steps

- Talk to your primary care doctor and specialist
- Find your ADRC
- Take a deep breath and stay a step ahead.

Transition Resources

– National Resource

www.gottransition.org

HEALTH TRANSITION WISCONSIN

SUPPORTING YOUTH TO ADULT HEALTHCARE

www.healthtransitionwi.org

Transition Resources

www.pacer.org

https://wisewisconsin.org/up-to-me/

Additional Tools & Resources

Providers and Teens Communicating for Health

www.patch.org

Wisconsin Board for People with Developmental Disabilities

www.wi-bpdd.org

Self-Directed Health Care Kit

Contact information

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Thank you!