



Bridging the Gap

Bridging the Gap:
Transition from Pediatric to Adult Health Care



Southern Regional Center
Children and Youth with
Special Health Care Needs



Presenters

Tim Markle

Parent

Youth Health Transition Initiative

Children and Youth With Special Health Care Needs

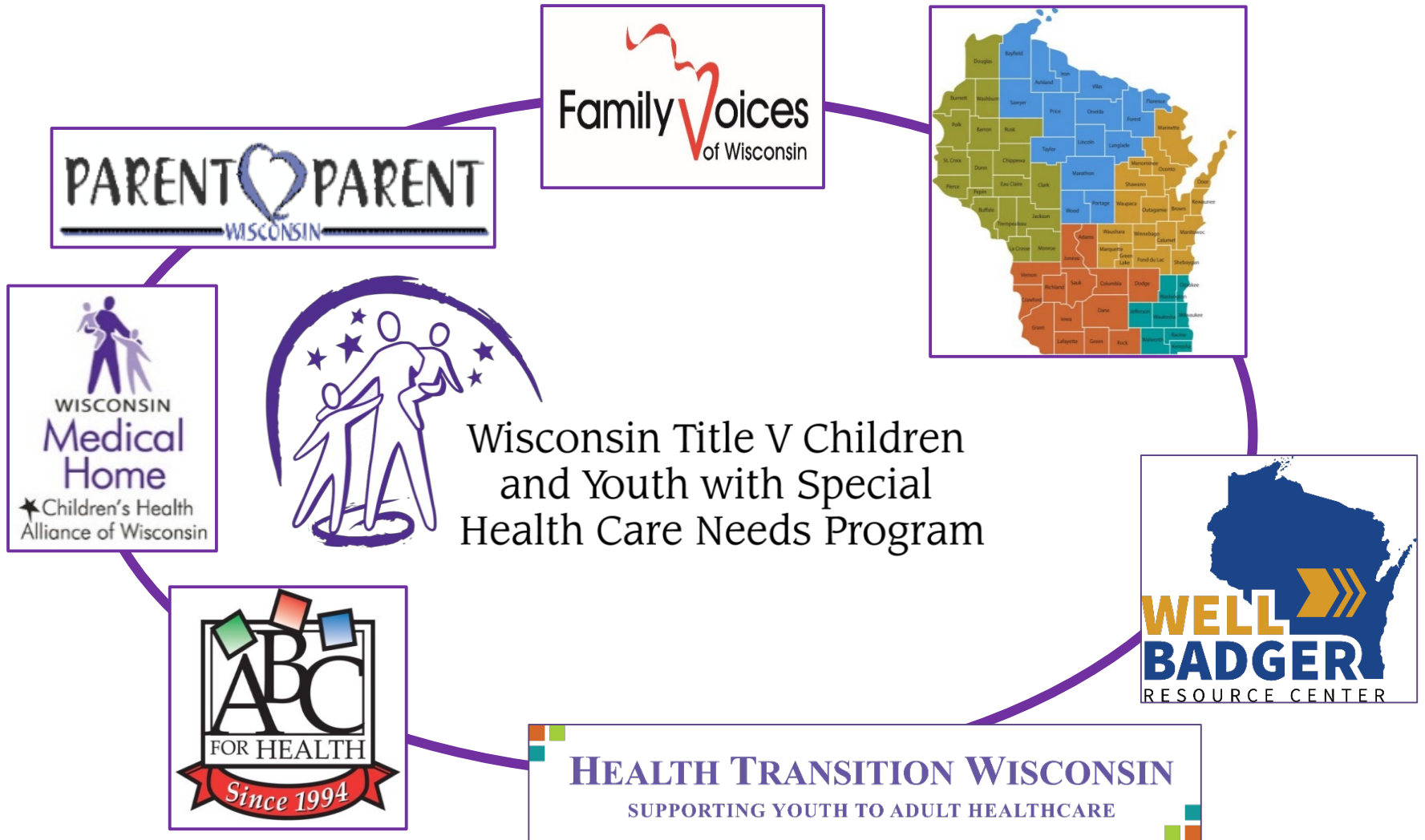
Southern Regional Center Director

Hunter Markle

Young Adult

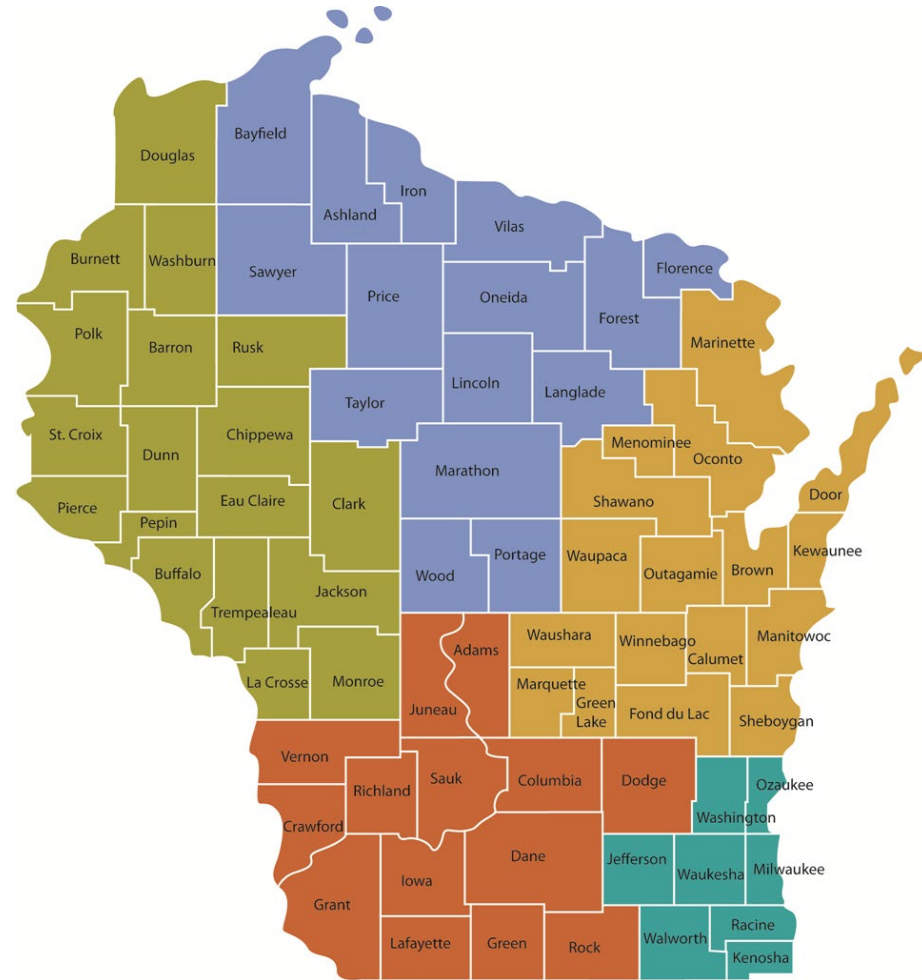
Who we are

Primary Network in Wisconsin



5

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

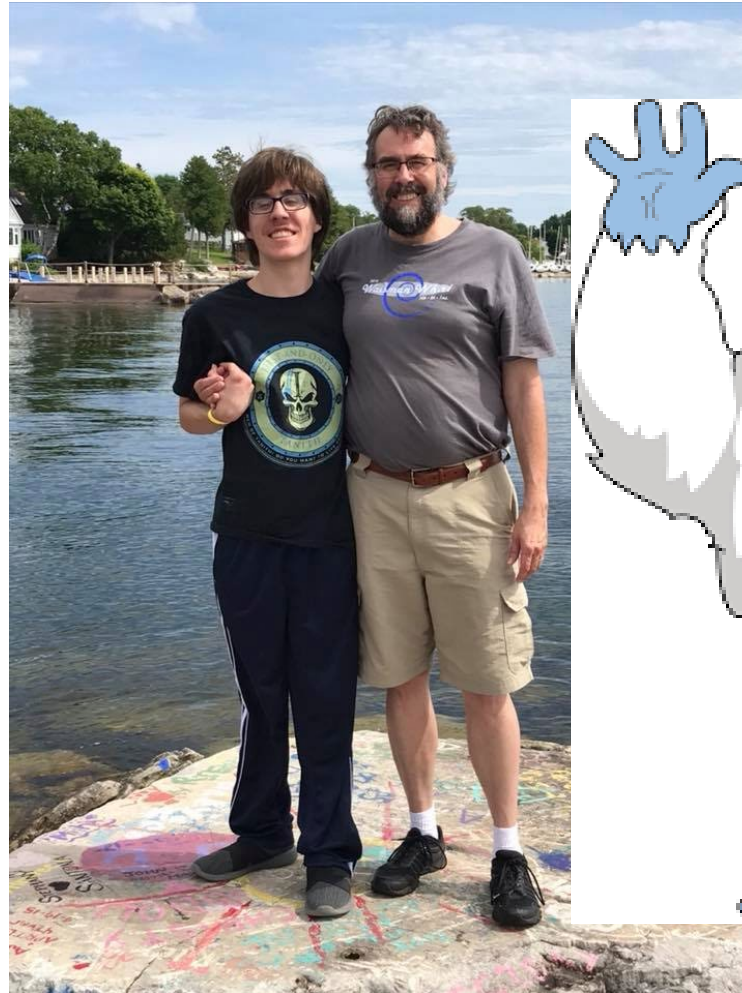
- Supports health care providers and organizations moving transition efforts forward within systems
- Facilitates *Transition Learning Community*, a virtual statewide network sharing best practices around transition
- *Health Transition Wisconsin* website and community outreach
- Disseminates health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

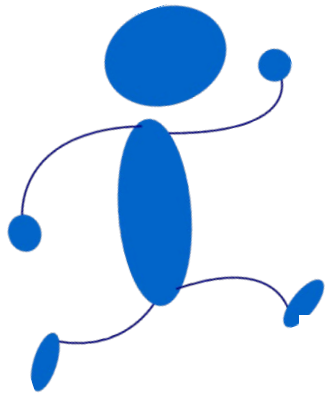
ADULT

AGE 16 DRIVE

AGE 18

AGE 21 DRINK - RESPONSIBLY

Stay a Step Ahead



Age
12-14



Age
15-17

Age
18 &
up

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
<input type="checkbox"/> I am able to care for all my needs	<input type="checkbox"/> Text-to-speech technology
<input type="checkbox"/> I need a little bit of help to care for my needs	<input type="checkbox"/> Assistive Listening Systems
<input type="checkbox"/> I need a lot of help to care for my needs	<input type="checkbox"/> ASL/Interpretation technology
<input type="checkbox"/> I need help to care for all my needs	<input type="checkbox"/> Other technology:
	<input type="checkbox"/> 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)
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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)
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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).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I can name 2-3 people who can help me with my learning differences, disability, medical, or mental health needs in an emergency.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Before a doctor's visit, I prepare questions to ask.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know to ask the doctor's office for accommodations, if needed.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I have a way to get to my doctor's office.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know the name(s) of my doctor(s).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know or I can find my doctor's phone number.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know how to make my doctor's appointments.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I carry my health information with me every day (e.g. insurance card, emergency phone numbers).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know my food allergies.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know the amount of the medicines I take.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know when I need to take my medicines.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know how to read and follow the direction labels on my medicines.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know what to do when I run out of my medicines.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know my medicine allergies.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>



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.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know how to ask questions when I do not understand what my doctor says.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know my allergies to medicines.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know my family medical history.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I talk to the doctor instead of my parent/caregiver talking for me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I see the doctor on my own during an appointment.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know when and how to get emergency care.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know where to get medical care when the doctor's office is closed.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I carry important health information with me every day (e.g., insurance card, emergency contact information).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know that when I turn 18, I have full privacy in my health care.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know at least one other person who will support me with my health needs.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know how to find my doctor's phone number.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know how to make and cancel my own doctor appointments.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I have a way to get to my doctor's office.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know how to get a summary of my medical information (e.g., online portal).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know how to fill out medical forms.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know how to get a referral if I need it.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know what health insurance I have.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know what I need to do to keep my health insurance.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I talk with my parent/caregiver about the health care transition process.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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

I know my own medicines.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know when I need to take my medicines without someone telling me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know how to refill my medicines if and when I need to.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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

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>

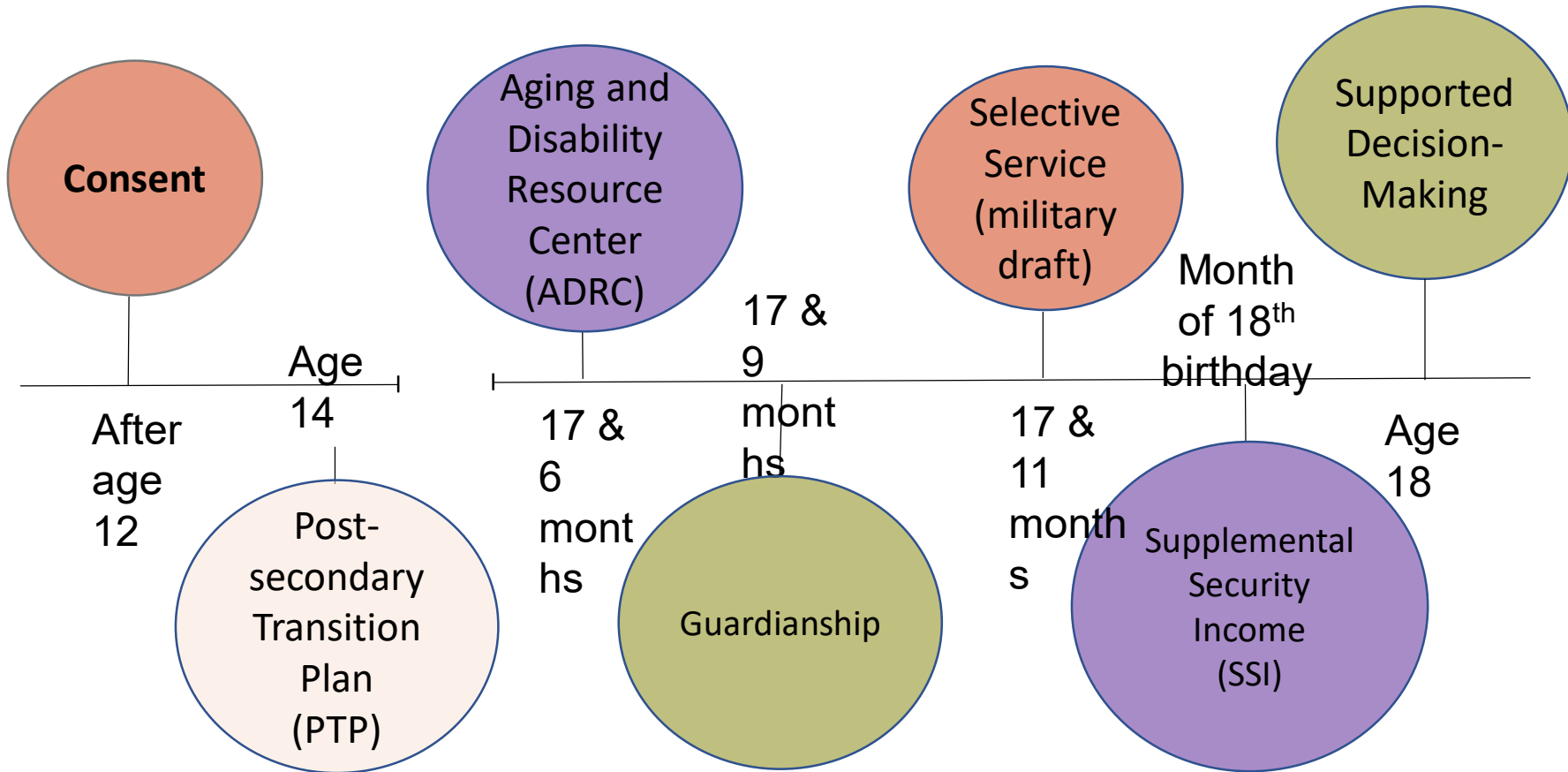
www.witransition.com



Self-Advocacy

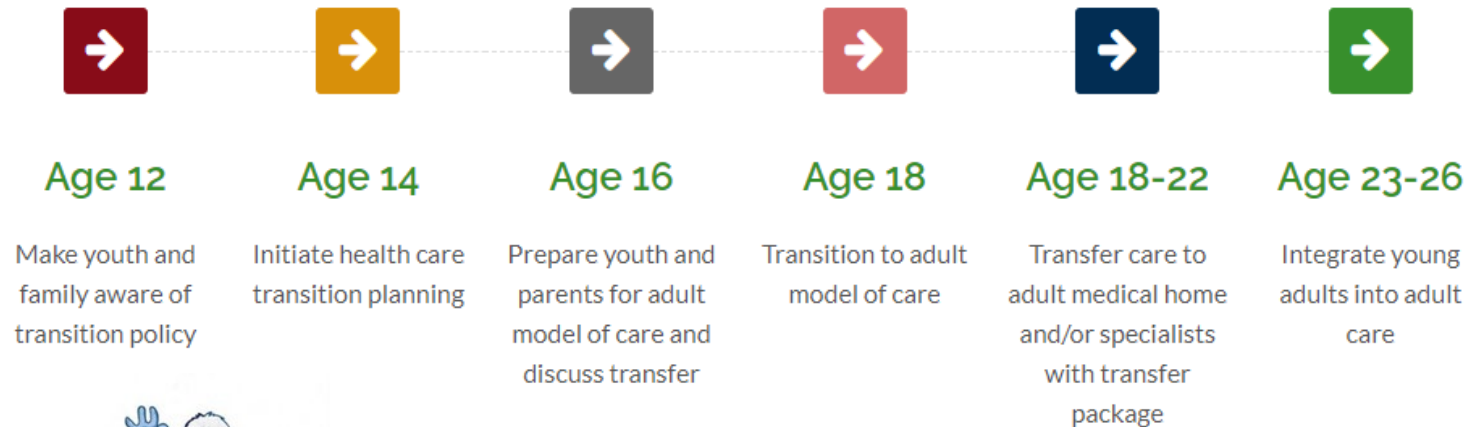
- Advocating for yourself in an effective manner- at school, work, or with those who are perceived as having power over you, shifts the dynamics of those relationships
- Self-advocacy also means that you get to choose when to pick your battles
- Self-advocacy can be a great source of self-care
- Learn 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



<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



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

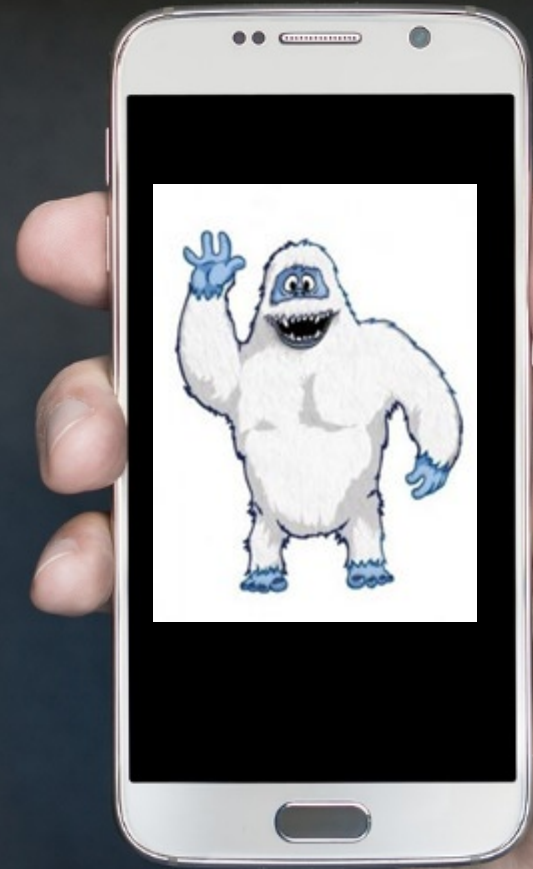
www.patch.org



Self-Directed
Health Care Kit

Contact information

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Thank you!