



Bridging the Gap

Bridging the Gap:
Transition from Pediatric to Adult Health Care

Presenters

Tim Markle

Parent

Youth Health Transition Initiative

Children and Youth With Special Health Care Needs

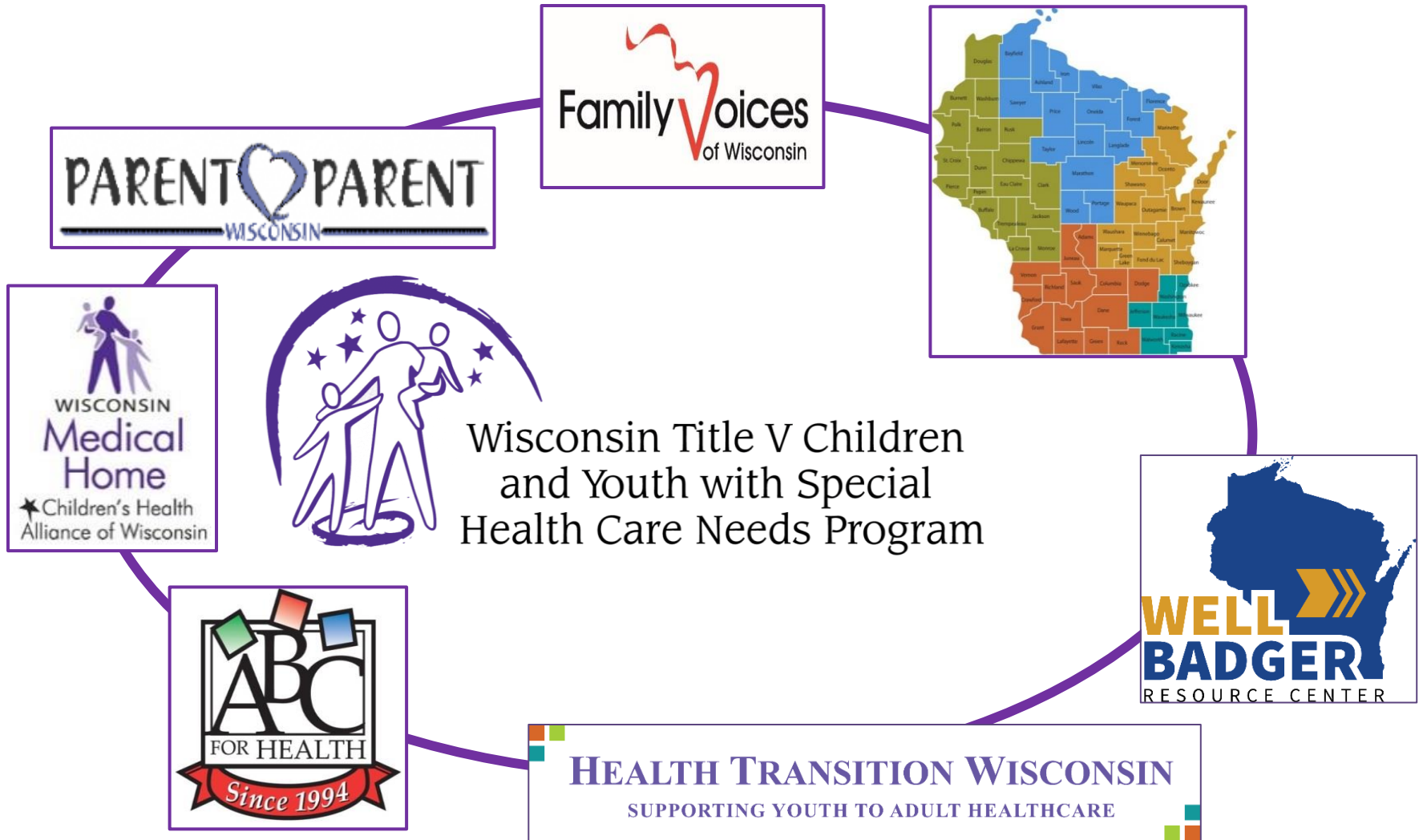
Southern Regional Center Director

Hunter Markle

Young Adult

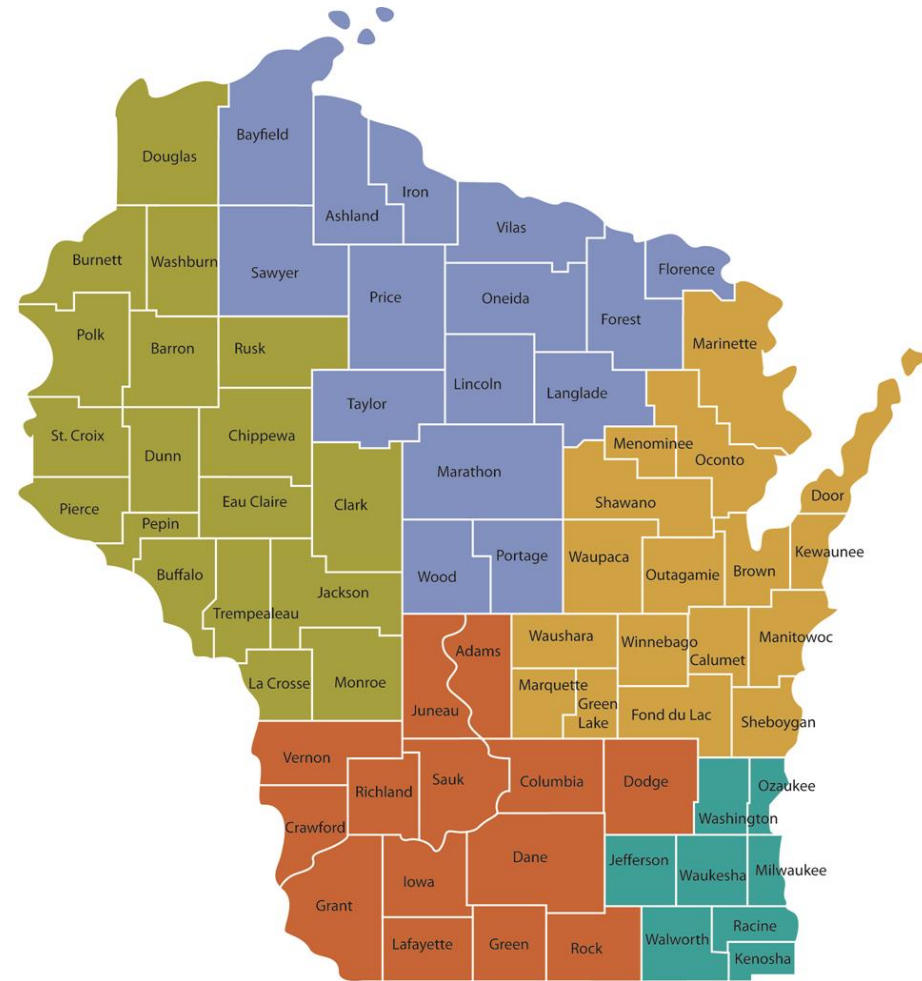
Who we are

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

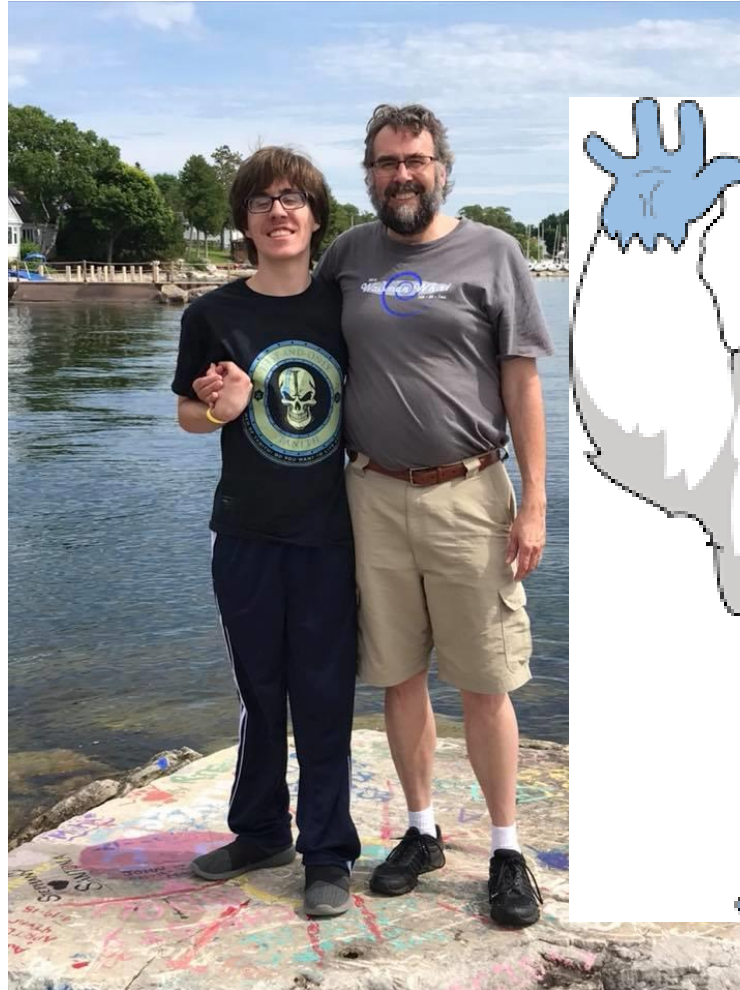
- Supports health care providers and organizations moving transition efforts forward within systems
- Facilitates *Transition Learning Community*, a virtual statewide network sharing best practices around transition
- *Health Transition Wisconsin* website and community outreach
- Disseminates health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

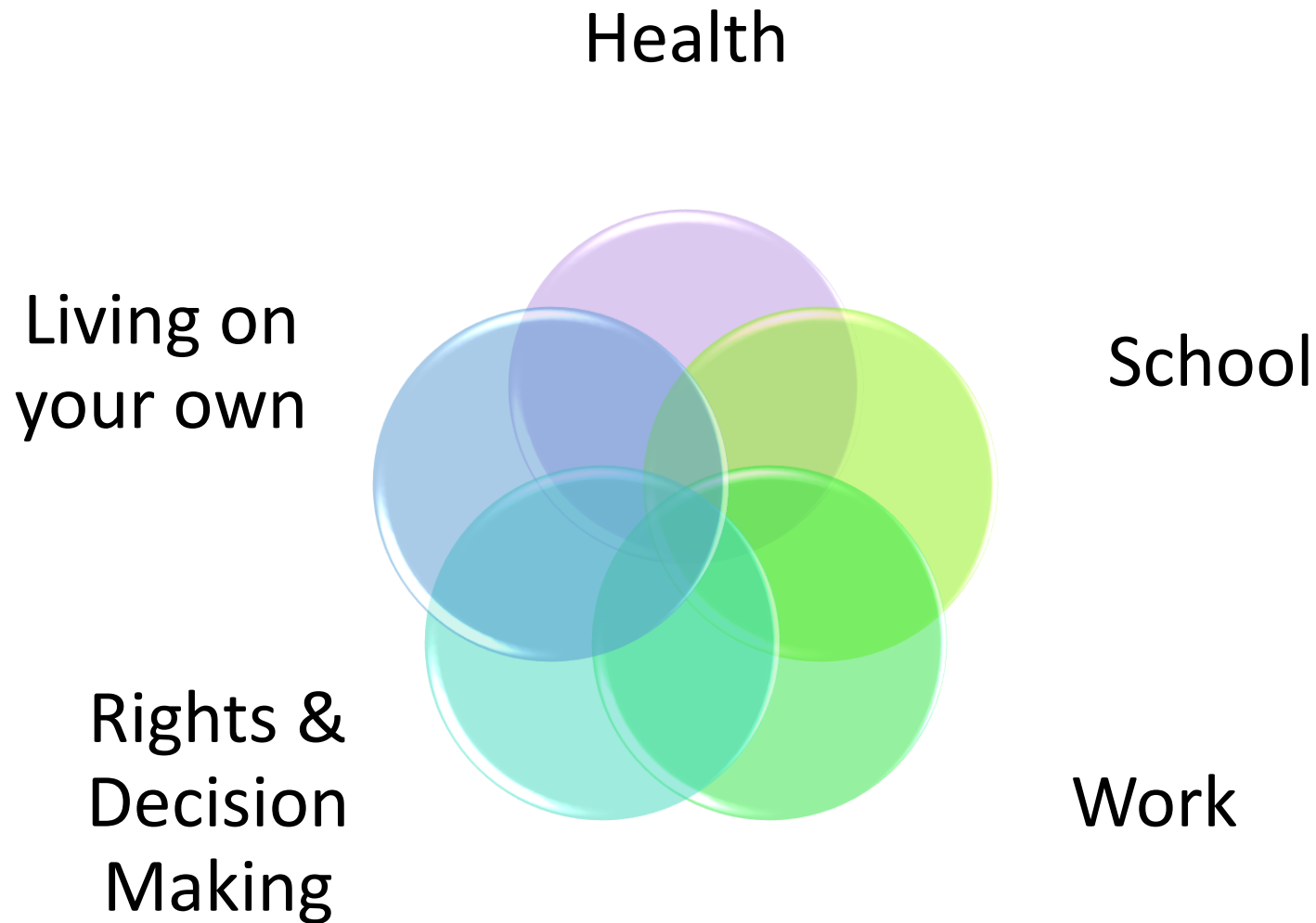
Increased independence.

Success in day to day life.

Opportunity for secondary education.

Working.

Transition is a process



When do other transitions occur?

AGE 16

DRIVE

AGE 18

VOTE

ADULT

AGE 21

DRINK - RESPONSIBLY

When do other transitions occur?

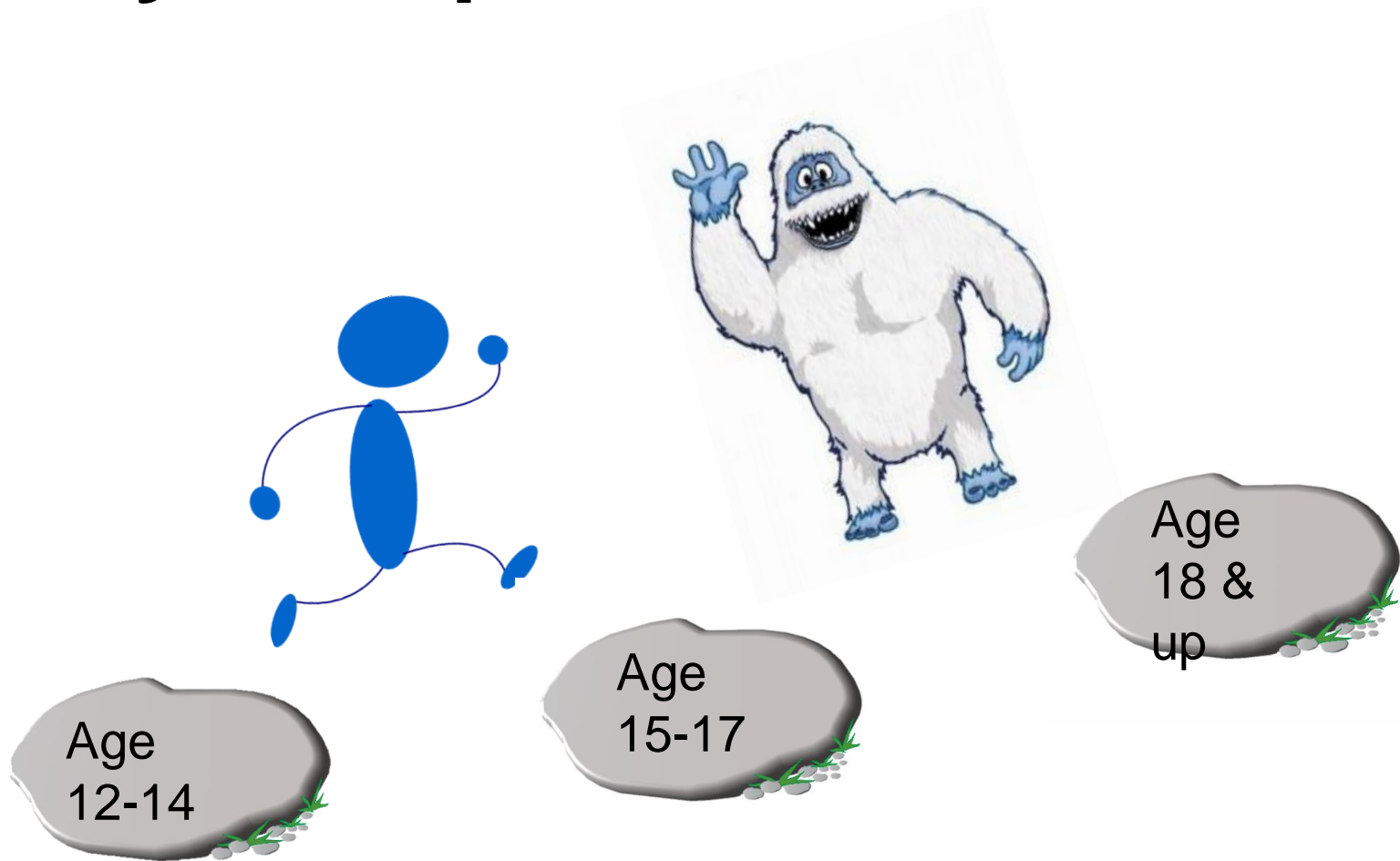
ADULT

AGE 16 DRIVE

AGE 18 VOTE

AGE 21 DRINK - RESPONSIBLY

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?



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 not	1	2	3	4	5	6	7	8	9	10 very
How confident do you feel about your ability to move to a doctor who cares for adults before age 22?										
0 not	1	2	3	4	5	6	7	8	9	10 very

MY HEALTH & HEALTH CARE	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	NO	I WANT TO LEARN	YES
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"/>

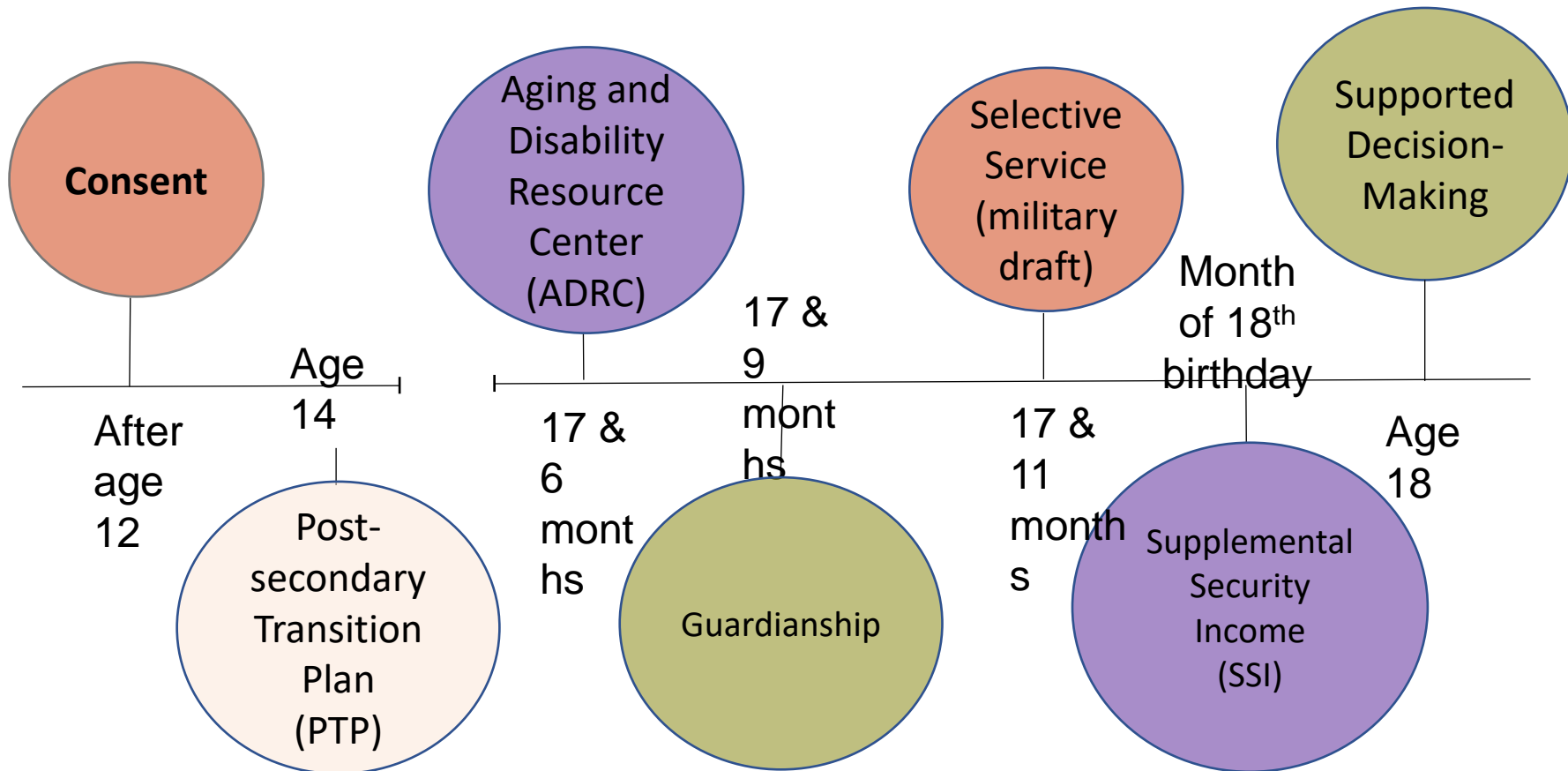
WHICH OF THE SKILLS LISTED ABOVE DO YOU MOST WANT TO WORK ON?

Readiness Assessment

Health Care Transition Readiness Assessment
for Students (English and Spanish)

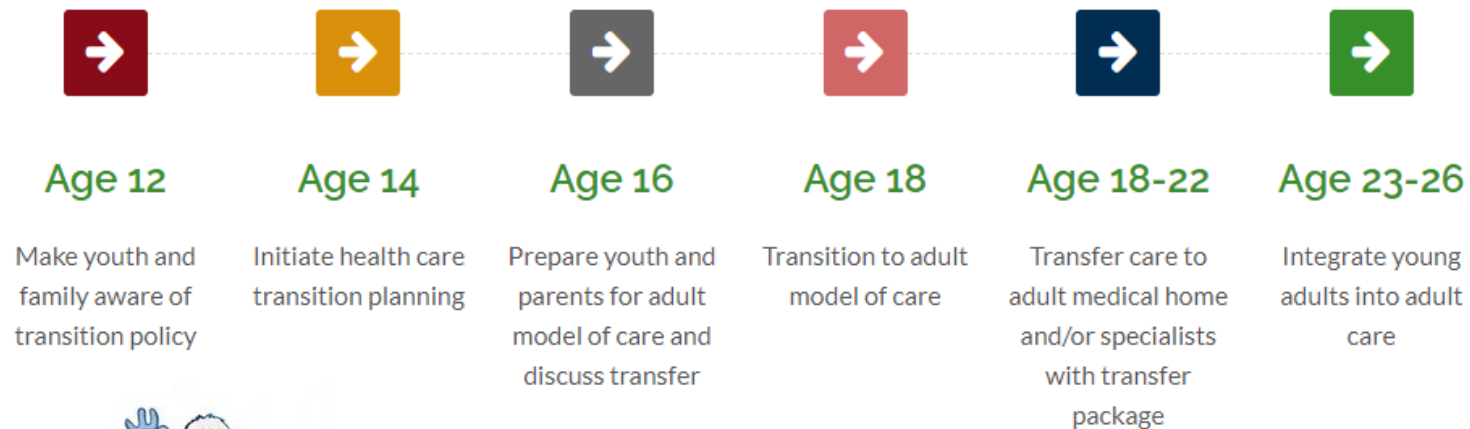
<https://www.gottransition.org/resources-and-research/non-health-transitions.cfm>

Transition in WI: Brief Timeline



Health Care Transition Timeline

RECOMMENDED HEALTH CARE TRANSITION TIMELINE



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

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

Guardianship

Parents need to resolve the issue of guardianship and/or related alternatives

- Guardianship is the legal power to care for another person and manage his/her affairs
 - ❖ Guardian of the Estate-finance
 - ❖ Guardian of the Person-personal/health care needs
 - ❖ Person may be appointed as both
- Some alternatives may include:
 - ❖ Health Care and/or Financial Power of Attorney
 - ❖ Conservatorship
 - ❖ Representative Payee
 - ❖ Dual Signature Accounts
 - ❖ Supported Decision-Making

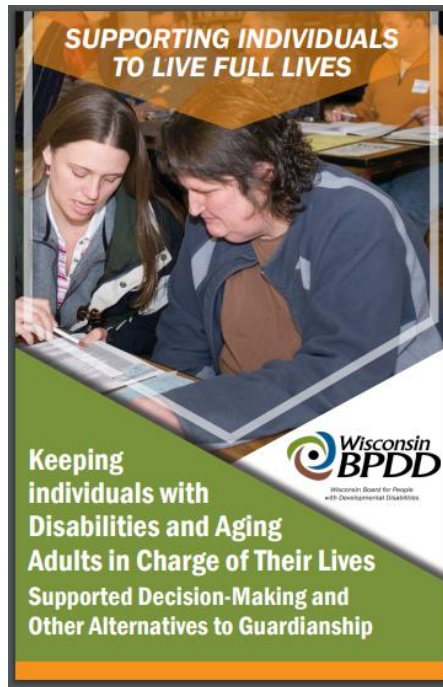
Supported Decision-Making (SDM)



- “A set of strategies to assist people with disabilities in using their own support system to take control of decisions in their lives”*
- Can be used as an alternative to guardianship or together with guardianship
- SDM agreement is a “legally recognized tool”**
- Youth names supporters to help with all aspects of life
- Allows for youth to have more freedom to make decisions as the youth grows and matures

* **Disability Rights WI, 2020

Supported Decision-Making



**Let's Talk About
SUPPORTED DECISION-MAKING**

Supported Decision-Making helps individuals* with disabilities and aging adults to make decisions about their lives. They choose the people they trust to help them gather and understand information, compare options, and communicate their decisions to others. It's how most people make decisions.

Supporting Individuals To Live Full Lives

Supported Decision-Making is an alternative to guardianship through which individuals get help from trusted family members, friends and professionals to help them understand the situations and choices they face, so they can make their own decisions. Supported Decision-Making enables individuals to ask for support where and when they need it. Supported Decision-Making agreements can be used for many kinds of decisions including medical, financial, housing and other life matters. Powers of attorney, representative payees and simple release of information forms can also help families provide the needed supports and safeguards without going to court and imposing guardianship restrictions.

Current decision-making support tools

Release forms	Supported Decision-Making Agreement	Representative Payee	Power of Attorney, (medical or financial)	Limited or Full Guardianship
Individual signs a release form authorizing a specific person access to certain information or records.	Individual makes all their own decisions. They identify a supporter/s to assist them.	Social Security Administration appoints an individual/org. to receive SSI/SSDI benefits for an individual who cannot manage their own.	Formal legal arrangements that permit others to act on the individual's behalf.	Transfers some or all decision-making authority from the individual to a court-appointed Guardian.

Less limiting ← → More limiting

* For the purpose of this publication, the term "individual" refers to an individual with disabilities and/or an aging adult.

<https://wi-bpdd.org/index.php/supporteddecision-making/>

Future Planning



- Letter of Intent
- Advanced Directives
- Put it in a safe place – digital file, phone, notebook

- Include Hopes, Dreams and Vision!



Decision Making

Who is making decisions about me?

Supported Decision Making

www.familyvoiceswi.org/

www.gottransition.org/resources/index.cfm

Guardianship or

Alternatives to Guardianship

www.wi-bpdd.org

Information on Supported Decision Making



- wi-bpdd.org/index.php/supporteddecision-making/
- arcwi.org/2018/04/13/supported-decision-making/
- disabilityrightswi.org/resources/supported-decision-making/
- gwaar.org/guardianship-resources
- dhs.wisconsin.gov/forms/f02377.pdf

Medical Financial Coverage



- Medicaid coverage
 - Children's remains active until age 19
 - Adults can apply in month of 18th birthday
- Staying on Parents' Insurance – “Adult Disabled Child”
 - Often children with disabilities may stay under parents' insurance policy indefinitely (past age 26)
 - Consult with your private insurance provider sooner than later

Social Security Disability and SSI

Social Security Disability Income (SSDI) – Based on work credits and work history.

- Medicare is provided 2 years after eligibility approved

Supplemental Security Income (SSI) – No work credits or work history required.

- Medicaid is provided at the time eligibility is approved

Supplemental Security Income Exceptional (SSI-E) - Additional State money added to the SSI payment each month

ADRC can complete the application!!!

Adult Long-Term Support Services



- ADRC – age 17 and 6 months
<https://www.dhs.wisconsin.gov/adrc/consumer/index.htm>
- Long-Term Waivers
 - Children's waivers can continue to age 22
 - Adult waivers can begin at age 18
- Adult Programs
 - IRIS
 - Family Care / Partnership

Path to Publicly Funded Long Term Care Services

At least 17 yrs &
6 mo old



Call ?

Aging and Disability
Resource Center



Provides Information
about services,
resources, and
programs

Eligibility
Determination



Functional Screen
Financial Eligibility

Options/Enrollment
Counseling



Counsel individuals
about eligibility for
various programs and
benefits

Managed Care
Organization (MCO)
or Care Management
Organization (CMO)

LTC Services, Family
Care or Partnership



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>

Disclosure

Who do I tell? How? When?

- Higher Education
- Employment

Self awareness of strengths and limitations

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.



Please, don't hesitate to contact us!



We've got the
Talent
Time
and Tools
to make Transitions as easy as
possible!

To find an ADRC in your County visit:
<https://www.dhs.wisconsin.gov/adrc/consumer/index.htm>

For more Youth in Transition materials visit:
<http://www.adrceagle.org/about-us/youth-in-transition/>

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

Tim Markle
Southern Regional Center
for CYSHCN
608-262-8033
tmarkle@wisc.edu





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Thank you!