

Now is the Time  
August 13-14, 2019  
UW Whitewater



Bridging the Gap:  
Moving from Shared Health  
Management to  
Self-Health Management  
Youth Health Transition Improving Outcomes



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



# TRANSITION READY! COMMUNITY EDITION

Bridging the Gap:

Moving from Shared Health Management to  
Self-Health Management

Youth Health Transition Improving Outcomes



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



# Presenters

- Tim Markle, MA  
Southern Regional Director  
Children and Youth With Special Health  
Care Needs  
Youth Health Transition Team

Who's Here?

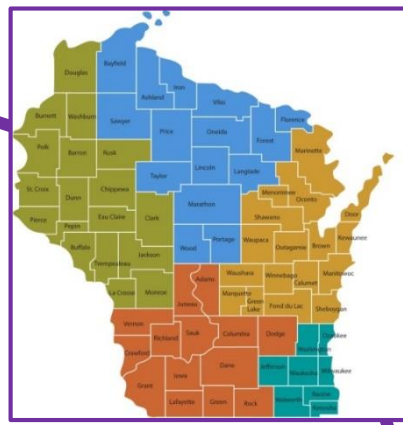
Who we are

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# CYSHCN Network of Support



**FamilyVoices**  
of Wisconsin



**PARENT  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



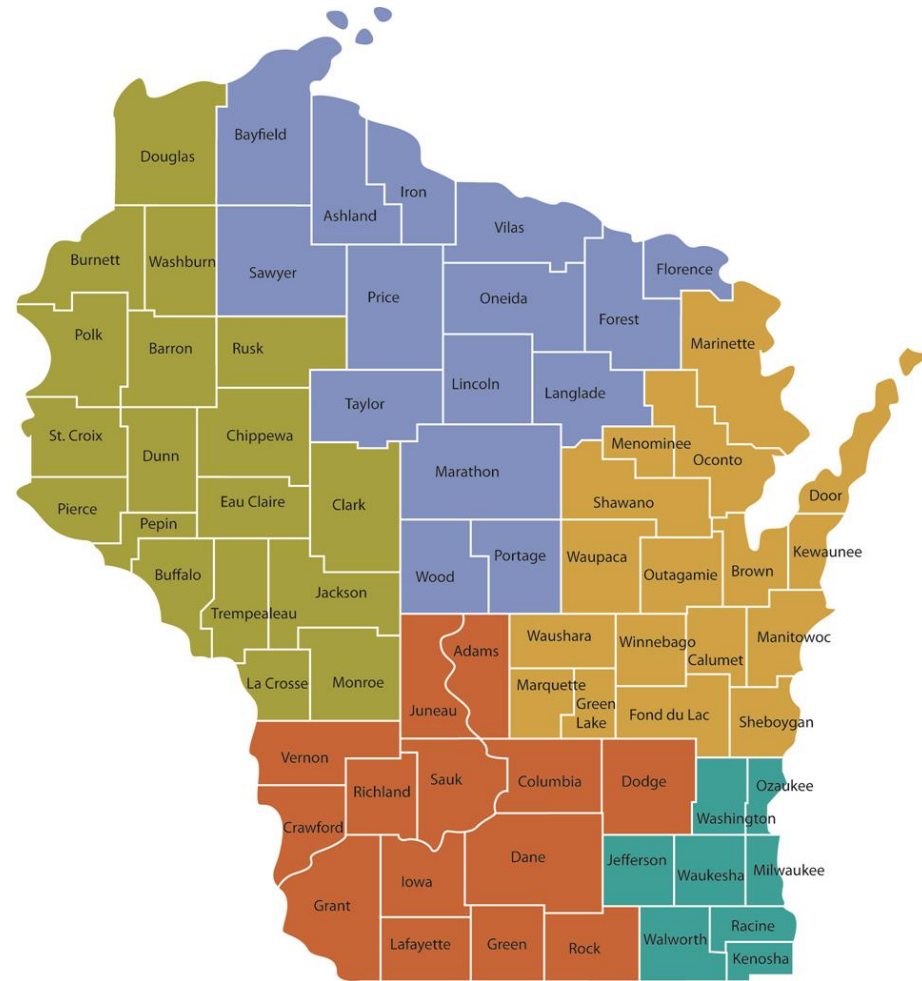
**ABC**  
FOR HEALTH  
*Since 1994*



**HEALTH TRANSITION WISCONSIN**  
SUPPORTING YOUTH TO ADULT HEALTHCARE

# 5

## Regional Centers Wisconsin



# Statewide Initiative





# Where We're Going

1. What is Health Care Transition anyway?
2. What is Self-Health?
3. Introduce and try out the Readiness Assessment for Parents & Youth
4. Introduce the Eight Tools for Health Care Transition/Self-Health
5. Discuss ways to include health and health care discussions in school, work and every day life



# What is Self-Health?

Knowing and communicating about my health.

# What is Self-Health?

- Knowing my own body/mind
- Knowing warning signs of distress
- Medications
- Appointments
- Support team
- Emergencies
- Preparing for challenges
- Overcoming challenges

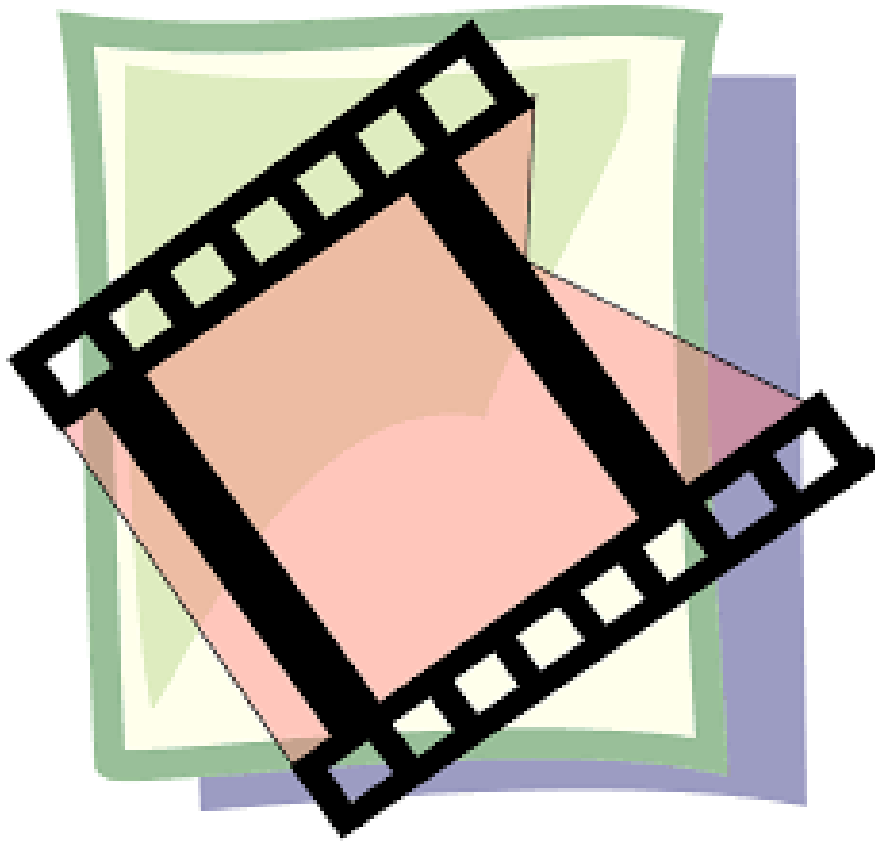
# What is Health Care Transition?

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

# Youth Health Transition



# Personal Story Time

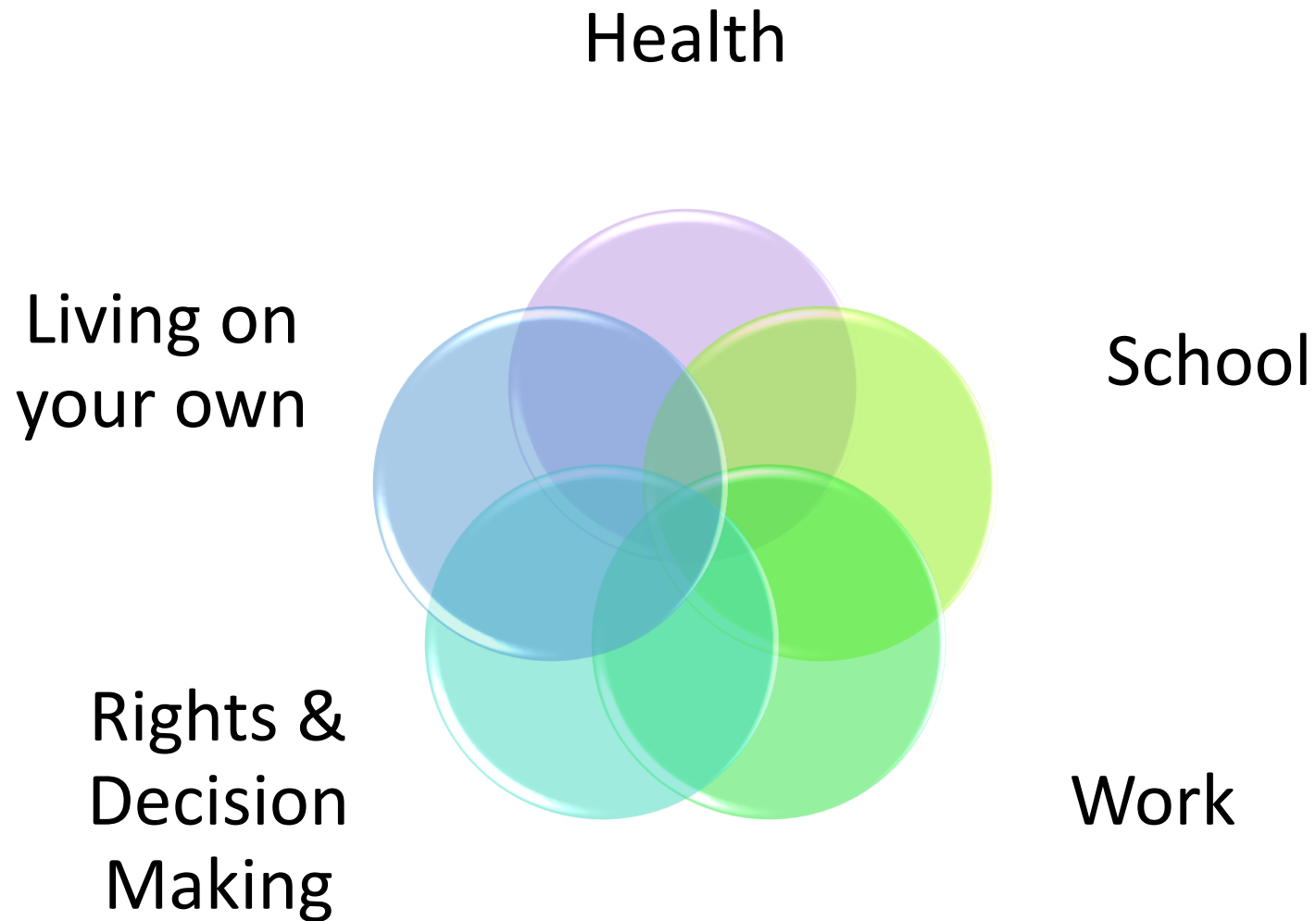


Who needs to  
think about  
transition?

Teens who are, or  
will be turning 18.

Especially if  
identified with  
a disability or  
health care need.

# Transition is a process





# Skills lead to Participation

Table groups: Skills set progression

Getting dressed

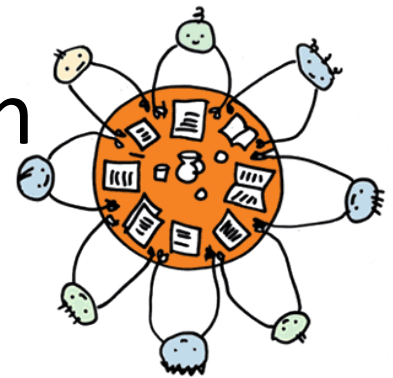
Cooking an egg

Driving a car

Talking about your health

Doing a quadratic equation

Taking multiple meds



# Why does self-management matter?

- Better health outcomes
- Improved adherence
- Increase ability to overcome challenges and solve problems

# Self-Management? Really???

Self-Management is really  
Shared Management

Dependency

Development

Differential Epidemiology

# Self-Management Behaviors

- Monitor symptoms
- Avoid triggers
- Manage symptoms
- Administer medication/treatment
- Adjust medication/treatment
- Manage tech/devices
- Attend to diet

# Self-Management Behaviors

- Prevent crisis and/or flares
- Problem-solve
- Implement action plan when needed
- Accommodate limitations
- Cope with functional impact
- Cope with emotional stress
- Prevent/manage complications

# Readiness Assessment

What do you already know about your health?



# Eight Health Transition 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

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





# About Me



- What do I understand about me?
  - Describe my health and levels of feeling good
- How do I communicate?
- What preferences do I have?
- Who do I tell what? DISCLOSURE



# How To Make A Decision



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

By Gary and Joy Lundberg

# Information on Supported Decision Making



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

# Health Insurance



## Wheel of Health!



# EMERGENCY CONTACTS





# iPhone Users



- Open Health and tap Medical ID > Edit.
- Enter your emergency contacts and other health information. Remember, only include what you want others to see!
- Turn on 'Show When Locked' to make your Medical ID available from the Lock screen.
- When you're finished, tap Done.



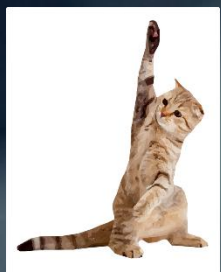
# Android Users



- Touch the orange Contacts icon.
- Touch the Groups icon that looks like two heads. A list of groups you can assign your contacts to will come up.
- Touch ICE - emergency contacts.
- Touch the plus sign.
- Either Create Contact or Add Existing Contact.

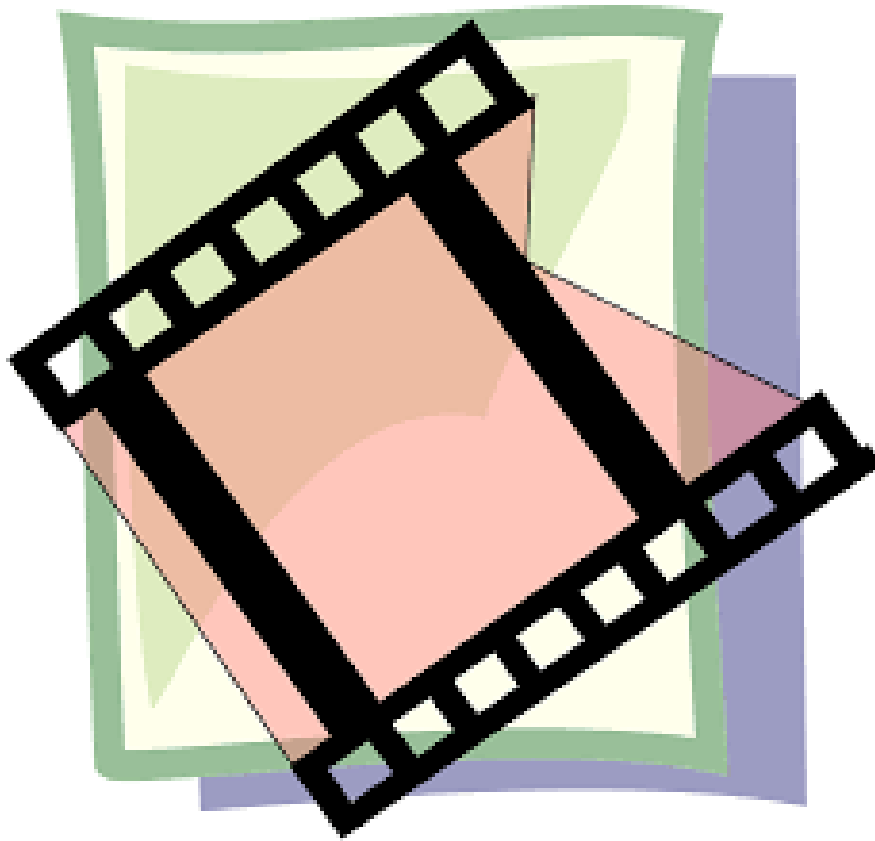


# Who You Gonna Call?





# Youth Health Transition



# APPOINTMENTS



Who do I call?

What kind of appointment is it?

When am I available?

How am I going to get there?

How will I remember to go?

# APPOINTMENTS



Will I always see my doctor?

What about at night?

Can someone come with me?

Do you cover my insurance?

Online vs phone

# MEDICATIONS



Learning about medications

Effects of medications

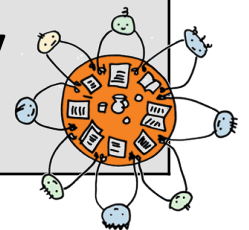
Refilling medications



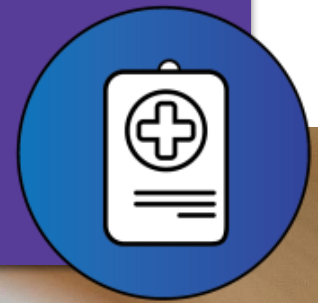
# Tips About Medications



Medication	Intended Purpose	Side Effects
Amoxicillin	Kills germs	Upset tummy
Albuterol	Helps breathe better	Feel all jazzed up
Benadryl	Stops the itching	Sleepy



# HEALTH SUMMARY



Condition or Diagnosis

Surgeries

Allergies

Medications

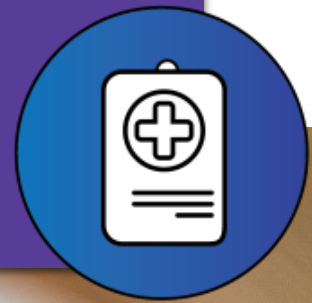
# Tips On A Health Summary



## American College of Physicians Condition-Specific Tools

- Intellectual and Developmental Disabilities (IDD)
- Physical Disabilities
- Type 1 Diabetes
- Turner Syndrome
- Growth Hormone Deficiency
- Systemic Lupus Erythematosus
- Sickle Cell Disease
- Hemophilia
- End-Stage Renal Disease
- Juvenile Idiopathic Arthritis
- Congenital Heart Disease

# Tips On A Health Summary



Include a family health history.

Have a hard copy to carry with you.

It can be a basic summary  
or as creative as you want.



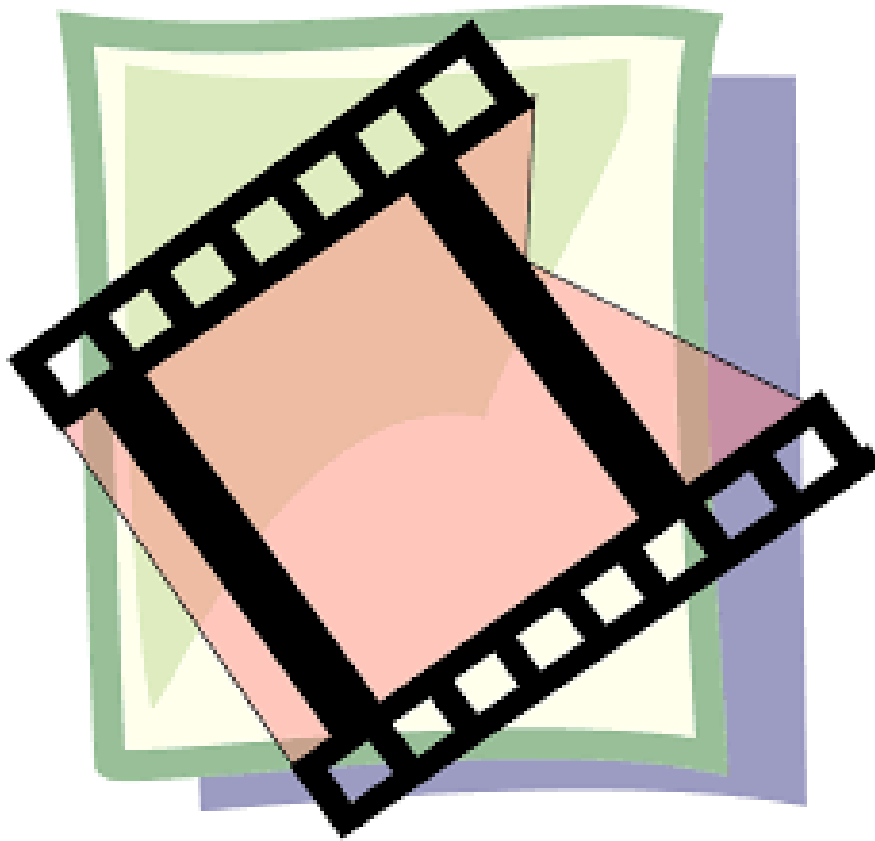
# ADULT PROVIDERS



# Dental



# Youth Health Transition





# 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 SPoC

## Shared Plan of Care (SPoC)

- Medical summary
- Strengths and preferences
- Negotiated plan of action
- Necessary attachments (POA, IEP, etc.)

## Wisconsin Medical Home Initiative

<https://www.chawisconsin.org/initiatives/medical-home/care-coordination/>

# Health and Employment

## Accommodations

- Self initiated
- Timing (who to tell and when)

## Other Considerations

- Transportation (timing)
- Breaks
- Unwritten rules

# 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](http://www.witransition.com)



# Health and Higher Education

## Accommodations

- Student initiated
- Disability center
- Rights and responsibilities

Emergency plan

In-Network care

Healthy behaviors



# Health and Self Advocacy

Who do I tell? How? When?

Self awareness of strengths and limitations

Making decisions

Supported Decision Making

[www.familyvoiceswi.org/](http://www.familyvoiceswi.org/)

[www.gottransition.org/resources/index.cfm](http://www.gottransition.org/resources/index.cfm)

Guardianship or

Alternatives to Guardianship

[www.wi-bpdd.org](http://www.wi-bpdd.org)

# Next Steps

- Complete readiness assessment;
- Start conversations
- Visit the Health Transition WI website and download the workbook; and
- Determine where Health Care Transition/Self-Health fits in your role.

# Transition Resources



[www.gottransition.org](http://www.gottransition.org)



**HEALTH TRANSITION WISCONSIN**

SUPPORTING YOUTH TO ADULT HEALTHCARE



[www.healthtransitionwi.org](http://www.healthtransitionwi.org)

# Transition Resources



[www.pacer.org](http://www.pacer.org)



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

# Additional Tools & Resources



Providers and Teens  
Communicating for Health

**[www.patch.org](http://www.patch.org)**



**Wisconsin Board for People  
with Developmental Disabilities**

**[www.wi-bpdd.org](http://www.wi-bpdd.org)**

Self-Directed  
Health Care Kit

# Contact information

**Tim Markle, MA**

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Thank you

Go and do amazing things!