Bridging the Gap

Bridging the Gap:
Transition from Pediatric to Adult Health Care
Presenters

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Who we are
Primary Network in Wisconsin

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

HEALTH TRANSITION WISCONSIN
SUPPORTING YOUTH TO ADULT HEALTHCARE
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

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.
Increased independence.

Success in day to day life.

Opportunity for secondary education.

Working.
Transition is a process

- Health
- School
- Work
- Rights & Decision Making
- Living on your own
When do other transitions occur?

**Age 16**  Drive

**Age 18**  Vote  Adult

**Age 21**  Drink - Responsibly
When do other transitions occur?

Age 16

Age 18

Drive

Vote

Get a job

Drink - responsibly

Adult
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?
## 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.

<table>
<thead>
<tr>
<th>Preferred name</th>
<th>Legal name</th>
<th>Date of birth</th>
<th>Today's date</th>
</tr>
</thead>
</table>

### 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.

1. How important is it to you to move to a doctor who cares for adults before age 22?
   - 0 = Not at all
   - 10 = Very

2. How confident do you feel about your ability to move to a doctor who cares for adults before age 22?
   - 0 = Not at all
   - 10 = Very

### My Health & Health Care

Please check the answer that best applies.

- **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?
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

- Consent
  - After age 12

- Post-secondary Transition Plan (PTP)
  - Age 14

- Aging and Disability Resource Center (ADRC)
  - 17 & 6 months

- Guardianship
  - 17 & 9 months

- Selective Service (military draft)
  - 17 & 11 months

- Supported Decision-Making
  - Month of 18th birthday

- Supplemental Security Income (SSI)
  - Age 18

- Aging and Disability Resource Center (ADRC)
  - 17 & 9 months

- Selective Service (military draft)
  - 17 & 11 months

- Supported Decision-Making
  - Month of 18th birthday

- Supplemental Security Income (SSI)
  - Age 18
Health Care Transition Timeline

**RECOMMENDED HEALTH CARE TRANSITION TIMELINE**

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

Eight Health Tools

**Health Transition Wisconsin**
Supporting Youth to Adult Health Care Transition

[https://healthtransitionwi.org/](https://healthtransitionwi.org/)

[https://healthtransitionwi.org/youth-families/](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 - finances
  ❖ 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

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 18\textsuperscript{th} 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

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

Counsel individuals about eligibility for various programs and benefits

LTC Services, Family Care or Partnership

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

LTC Services, Family Care or Partnership

IRIS

Include, Respect, I Self-Direct
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

got transition – 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

Self-Directed Health Care Kit

www.wi-bpdd.org
Contact information

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Thank you!

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