Bridging the Gap

Bridging the Gap:
Transition from Pediatric to Adult Health Care
Presenter(s)

Hunter Markle
Young Adult

Tim Markle
Parent
Youth Health Transition Initiative
Children’s Resource Center-South
Who we are
Wisconsin CYSHCN Network

Wisconsin Title V Children and Youth with Special Health Care Needs Program
Welcome to Build Your Bridge

Children’s Resource Centers

Formerly known as the CYSHCN Regional Centers
Note: Centers will keep their current phone numbers for already established contacts.

North
866-640-4106

West
800-400-3678

Northeast
877-568-5205

South
800-532-3321

Southeast
800-234-5437

Wisconsin Wayfinder
Children’s Resource Network
dhs.wi.gov/wiscway/(877)WiscWay
Children’s Resource Center -South

Location:  Waisman Center, Madison
Phone:  608-265-8610
Toll Free:  800-532-3321
Director:  Tim Markle

crcsouth@waisman.wisc.edu
crcsouth.waisman.wisc.edu
Statewide Initiative

Health Transition Wisconsin
Supporting Youth to Adult Healthcare
WI Youth Health Transition Efforts

• Supports health care providers and organizations moving transition efforts forward within systems

• *Health Transition Wisconsin* website and community outreach

• Disseminates health transition resources to partners through trainings, exhibits and community partnerships

• Promote integrated transition planning
Where We’re Going

1. What is Health Care Transition (HCT) anyway?
2. What health care skills can be learned and practiced before adulthood?
3. How does HCT impact other areas of transition?
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
What are some parts of Health Care Transition?

Multi-year Process

1. Preparing for Transition (12 or younger)

2. Transfer of Care (usually 18-22 years old)

3. Fully Integrated into Adult Health Care (rest of their lives)
Who needs to think about transition?

Adolescents and Young Adults (AYA) their families, their schools, their employers, their community.

Especially if identified with a disability or health care need.
What is Health Care Transition?

Multi-year Process

1. Preparing for Transition
What might change

• Providers/hospital/procedure
• Decision making/information sharing/Supported Decision Making
  • Release of Information
  • Powers of Attorney
  • Guardianship
  • Supported Decision Making
What might change

• More information sharing
  Appointments (during and after hours)
  Prescription refills
  Access to electronic records

• Health Insurance
  Public
  Private/Family
  Both
  None?
Skills that can be worked on before 18

• Decision making
• Understanding health needs
• Making/checking into appointments
• Time alone with the doctor
• Filling prescriptions, taking medications, understanding side effects
• Emergency Contacts (phone, medical alert, card, etc.)
• About Me & Shared Plan of Care
Stay a Step Ahead

Age 12-14

Age 15-17

Age 18 & up
Readiness Assessment

What do you already know about your health?
Readiness Assessment

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.

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

| | 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?

| | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10
|---|---|---|---|---|---|---|---|---|---|---|
| Not | | | | | | | | | | very

**MY HEALTH & HEALTH CARE** Please check the answer that best applies.

<table>
<thead>
<tr>
<th></th>
<th>NO</th>
<th>I WANT TO LEARN</th>
<th>YES</th>
</tr>
</thead>
<tbody>
<tr>
<td>I can explain my health needs to others.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>I know how to ask questions when I do not understand what my doctor says.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>I know my allergies to medicines.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>I know my family medical history.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>I talk to the doctor instead of my parent/caregiver talking for me.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>I see this doctor on my own during an appointment.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>I know when and how to get emergency care.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>I know where to get medical care when the doctor’s office is closed.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>I carry important health information with me every day (e.g., insurance card, emergency contact information).</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>I know that when I turn 18, I have full privacy in my health care.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>I know at least one other person who will support me with my health needs.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>I know how to find my doctor’s phone number.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>I know how to make and cancel my own doctor appointments.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>I have a way to get to my doctor’s office.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>I know how to get a summary of my medical information (e.g., online portal).</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>I know how to fill out medical forms.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>I know how to get a referral if I need it.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>I know what health insurance I have.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>I know what I need to do to keep my health insurance.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>I talk with my parent/caregiver about the health care transition process.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>

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

<table>
<thead>
<tr>
<th></th>
<th>NO</th>
<th>I WANT TO LEARN</th>
<th>YES</th>
</tr>
</thead>
<tbody>
<tr>
<td>I know my own medicines.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>I know when I need to take my medicines without someone telling me.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>I know how to refill my medicines if and when I need to.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>

**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)

All transitions are have steps

Health

Housing & Life

Rights & Decision Making

School

Work
Why is health so important?

Increased independence

Success in day to day life

Post secondary education success

Working

Housing and Life
Success needs a foundation

Housing and Life  Rights & Decision Making  School  Work

Health
School and Health

High School

Health
School and Health

- Post Secondary School
- Health
Employment and Health

Work

Health
Housing, Life and Health

Housing and Life

Health
Rights and Health

Rights & Decision Making

Health
Rights and Health

Current decision-making support tools

- **Release forms**
  Individual signs a release form authorizing a specific person access to certain information or records.

- **Supported Decision-Making Agreement**
  Individual makes all their own decisions. They identify a supporter/s to assist them.

- **Representative Payee**
  Social Security Administration appoints an individual/org. to receive SSI/SSDI benefits for an individual who cannot manage their own.

- **Power of Attorney, (medical or financial)**
  Formal legal arrangements that permit others to act on the individual’s behalf.

- **Limited or Full Guardianship**
  Transfers some or all decision-making authority from the individual to a court-appointed Guardian.

*For the purpose of this publication, the term "individual" refers to an individual with disabilities and/or an aging adult.*
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
Bring health into your transition area

High School
Post-secondary
Therapy
Pre-employment skills
Employers
Employment agencies
DVR
ADRC
Housing support
What is Health Care Transition?

Multi-year Process

1. Preparing for Transition (12 or younger)
2. Transfer of Care (usually 18-22 years old)
3. Fully Integrated into Adult Health Care (rest of their lives)
Transition Resources

Southern Regional Center for Children and Youth with Special Health Care Needs
www.cyshcn.waisman.wisc.edu

Transition Talks Tuesdays (recorded videos)
https://cyshcn.waisman.wisc.edu/transition-talks-tuesdays-2/
Transition Resources

www.gottransition.org

Health Transition Wisconsin
Supporting Youth to Adult Healthcare

www.healthtransitionwi.org
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
Transition Resources

www.pacer.org

Providers and Teens Communicating for Health

www.patch.org

https://wisewisconsin.org/up-to-me/
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
Health and the Employment Division of Vocational Rehabilitation (DVR) [https://dwd.wisconsin.gov/dvr/job-seekers/transition/](https://dwd.wisconsin.gov/dvr/job-seekers/transition/)

Job Accommodation Network [https://askjan.org](https://askjan.org)
Supported Decision Making Toolkit

Supported Decision-Making Training (online)
April 10, 1-4pm from WI BPDD
More Information

Family Voices of Wisconsin
Transition to Adult Life Fact Sheets
https://familyvoiceswi.org/resource-library/

Wisconsin Integrated Transition Planning Project
https://integratedtransition.waisman.wisc.edu/
Stay a Step Ahead

Age 12-14

Age 15-17

Age 18 & up
Contact information

Tim Markle
Children’s Resource Center-South
608-262-8033
tmarkle@wisc.edu
Thank you!

Short (but very important) evaluation:

https://redcap.wisconsin.gov/surveys/?s=HHPPR93Y4A&session_name=8