Bridging the Gap

Bridging the Gap:
Transition from Pediatric to Adult Health Care
Hunter Markle
Young Adult

Tim Markle
Parent
Youth Health Transition Initiative
Children and Youth With Special Health Care Needs
Southern Regional Center Director
Who we are
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
Southern Regional Center

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

cyshcn@waisman.wisc.edu
waisman.wisc.edu/cshcn
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?
Personal Story Time
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)
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

For Providers/Clinics/Systems

https://www.gottransition.org/six-core-elements/
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.)
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.

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?

<table>
<thead>
<tr>
<th>Not</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10 Very</th>
</tr>
</thead>
</table>

How confident do you feel about your ability to move to a doctor who cares for adults before age 22?

<table>
<thead>
<tr>
<th>Not</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
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<th>8</th>
<th>9</th>
<th>10 Very</th>
</tr>
</thead>
</table>

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

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 medications. □ □ □

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 everyday (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)

All transitions are have steps

- Health
- Housing & Life
- Rights & Decision Making
- School
- Work
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
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.
Why is health so important?

Increased independence
Success in day to day life
Post secondary education success
Working
Housing and Life
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
Eight Health Tools

• Appointments
• Medications
• Health Summary
• About Me
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

Life
What is Health Care Transition?

Multi-year Process

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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
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)
WI Board for People with Developmental Disabilities

Supported Decision Making Toolkit

Supportive Decision Making and Guardianship
October 3, 6:15-7:15pm
https://cyshcn.waisman.wisc.edu/transition-talks-tuesdays-sauk-prairie-school-district/
Family Voices of Wisconsin

Transition to Adult Life Fact Sheets

https://familyvoiceswi.org/resource-library/

Thinking about Supported Decision Making (Virtual Workshop)

November 15, 6:00pm

https://familyvoiceswi.org/events-calendar/
Stay a Step Ahead

Age 12-14

Age 15-17

Age 18 & up
Contact information

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

Short (but very important) evaluation:

https://redcap.wisconsin.gov/surveys/?s=HHPPR93Y4A&session_name=8
This form is to help me better communicate with you, my doctor.
Thank you for taking care of me today.

INFORMATION ABOUT ME AND DECISION MAKING

FULL NAME: 
ADDRESS: 
MY PHONE NUMBER: 
NAME OF EMERGENCY CONTACT: 
PHONE NUMBER FOR CONTACT: 

I can make my own decisions about my health care: ☐ Yes ☐ No 
If no, who assists me in making decisions about my health care: 
This person is my: ☐ Family ☐ Caregiver ☐ Other

To contact this person, please call: 

I live: ☐ By Myself ☐ With my family ☐ With my caregiver ☐ With roommates 
☐ In a group home ☐ Other

SOME WAYS YOU CAN HELP ME STAY CALM AND BETTER UNDERSTAND

☐ Talk slowly 
☐ Write it down 
☐ Use sign language 
☐ Use a voice app 
☐ Talk to my caregiver too 
☐ Other

Pictures help me: ☐ Yes ☐ No
Bright lights bother me: ☐ Yes ☐ No
A lot of noise bothers me: ☐ Yes ☐ No

Describe the reason for your appointment (include your symptoms)?

Do you have any medical problems that you go to the doctor for? ☐ Yes ☐ No
What are they?

Do you take any medication at home every day? ☐ Yes ☐ No
By prescription? ☐ No
☐ Yes, list the names and dosages

Over the counter? ☐ No 
☐ Yes, list the names and dosages

Do you have allergies to medicines? ☐ Yes, please list

Dr. Leah Ederer
Health Care Changes Too!
Bridging the Gap from Adolescent to Adult Health Care

Transition Talk Tuesdays
10/10/2023
Liz Kennedy, Transition Coordinator, SPSD
Tim Markle,
Southern Regional Center for Children and Youth with Special Health Care Needs and the Wisconsin Youth Health Transition Initiative, and
Hunter Markle
How Sauk Prairie School District helps with this process...

Transition Coordinator will:

- assist families in referring to the ADRC at 17.6 (see 09/26 TTT webinar for info on ADRC)
- coordinate with any outside agencies with whom you may be collaborating
- share healthcare toolkits, medical record/medication folders
- parent portfolios - available in Spanish and English
- Wisconsin Transition Resource Guides - available in Spanish and English
- connect you with local Independent Living Centers
- connect you with school social workers who can assist you in connecting with applications for medical coverage
- help you plan through the PostSecondary Transition Plan (PTP) for the steps you need to take in this process
More Transition Talk Tuesdays Coming up...

Transition Tuesdays
9/19-10/24

✔ Sauk Prairie Transition: PTP, Post secondary education planning, financial aid discussion with college reps
✔ The ADRC, Long Term Supports and SSI application
✔ Guardianship and supported decision making – The continuum of support options
✔ Healthcare for people with disabilities
  - Working while on social security, Ticket to Work, PASS program, Benefits Analysis
  - Sauk Prairie Beyond 18 programs and employment
How to sign up for the other TTT sessions

Here is the link for families to sign up:
Registration -- https://go.wisc.edu/RegTTTSauk

Website -- https://go.wisc.edu/TTTSauk
Todas las charlas se interpretarán simultáneamente al español.
Para descargar un folleto en español. flyer
También está disponible una página de inscripción en español. https://go.wisc.edu/9g3174

All talks will be simultaneously interpreted into Spanish.
A registration site in Spanish is also available. https://go.wisc.edu/9g3174

Families can register online and we will also be offering in-person for those who do not have access to technology outside of school. I have reserved the BOE room for each of the evenings at 440 13th Street, Prairie du Sac, 53578

We had one virtual Transition Talk about Special Needs Trusts already. You can access that at the website to watch at any time.
Questions and Contact Information

Liz Kennedy
Transition Coordinator
Sauk Prairie School District
liz.kennedy@saukprairieschools.org
608.644-2863 * new number

Questions and special thanks to Tim Markle and our Spanish interpreters!