Empowering Students to be Ready to Take Charge of their Health Care as Adults

Wisconsin Association of School Nurses
April 27, 2023

Presenters

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Father and Curriculum Developer for Wisconsin Youth Health Transition Initiative

Disclosures

- None

Learner Objectives

1. Define Health Care Transition (HCT)
2. Describe the current status of HCT efforts
3. Summarize three barriers to HCT
4. Identify the possible roles of the school nurse in HCT
5. Describe the role of HCT in the IEP, IHP, Emergency Care Plan

Primary Network in Wisconsin

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"

-Pediatrics, 2018

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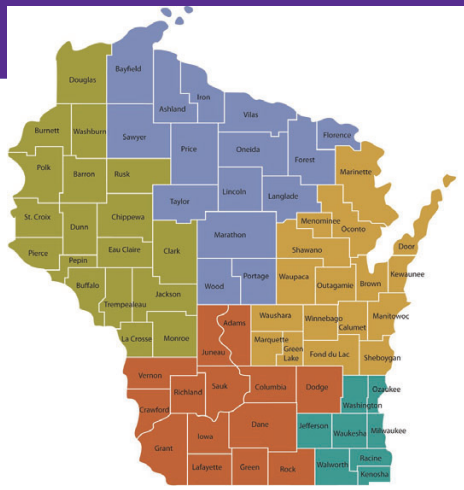
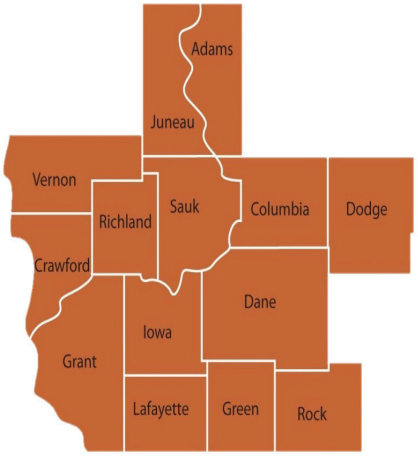
Regional Centers
Wisconsin



Southern Regional Center

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

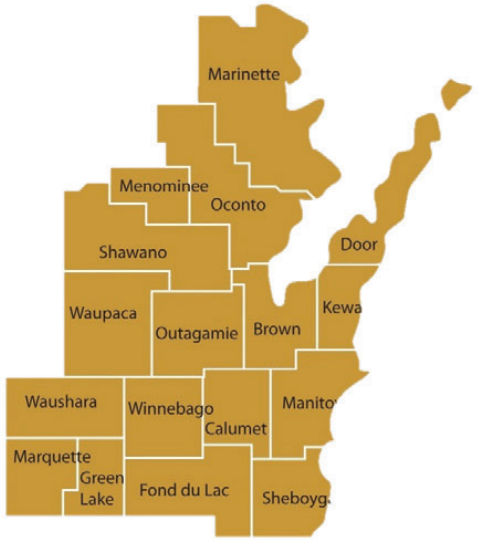
cyshcn@waisman.wisc.edu
waisman.wisc.edu/cshcn



Northeast Regional Center

Location: Neenah
Phone: 920-969-5325
Toll Free: 877-568-5205

infonerc@chw.org
northeastregionalcenter.org



Definition

- Heath Care Transition is the process of moving from a child to an adult model of health care with or without a transfer to a new clinician

Prepare → Transfer → Integrated

-Pediatrics, 2018

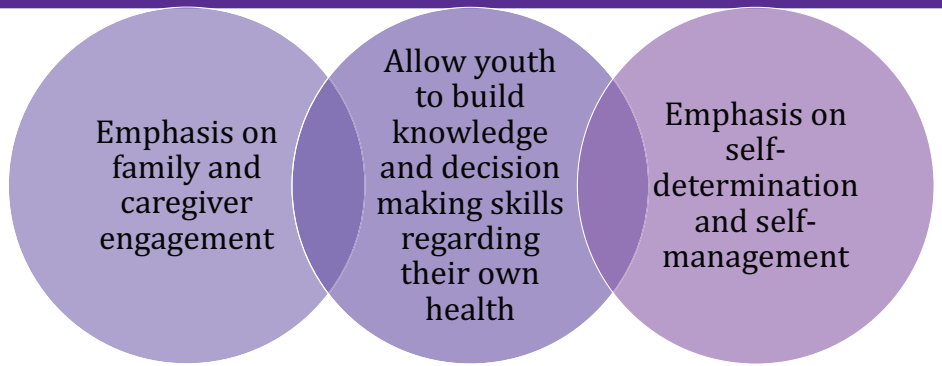
Guiding Principles

- PROCESS – start early and ongoing
- Recognize and acknowledge cultural beliefs and socioeconomic status
- Acknowledge individual differences

Guiding Principles (Continued)

- youth-centered, strength based focus
- Recognize vulnerabilities and need for population health approach
- Emphasis on health equity and elimination of health disparities

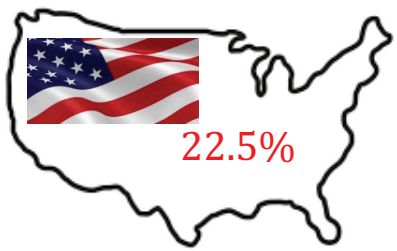
Guiding Principles (Continued)

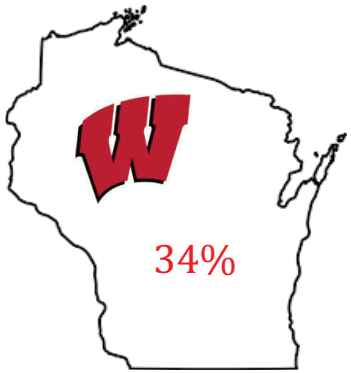


Measuring Transition Success

1. Youth had time alone with provider during their last preventative care visit
2. The provider worked with youth to gain self-care skills or understand the changes in health care that happen at age 18
3. The provider talked with the youth about eventually seeing providers who treat adults

How are we doing? 2019-20 Data



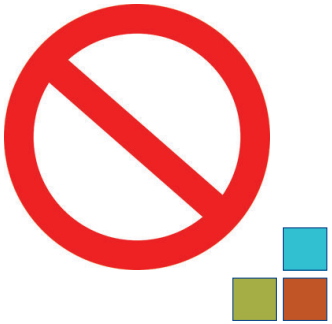


-2019-2020 National Survey of Children's Health, Wisconsin

Roughly 80% of CYSHCN in the US and >65% in WI don't receive transition services…And numbers are even more dismal for our "typical" kids without complex healthcare needs

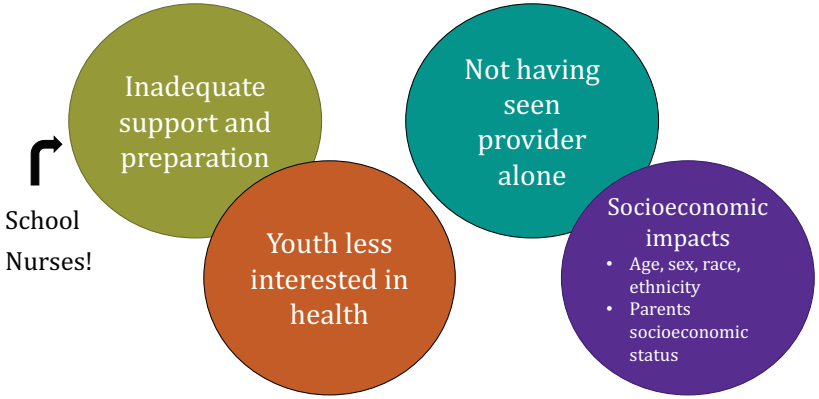
What are the Transition Barriers?

- Patient Barriers
- Inadequate Planning Barriers
- System Barriers



Patient Barriers: Fear
New health care system, hospital, provider…

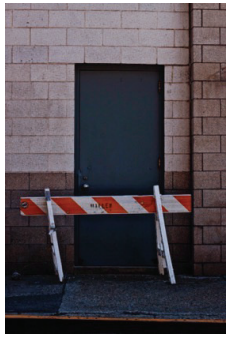
Inadequate Planning Barriers



Systems Barriers

System Barriers

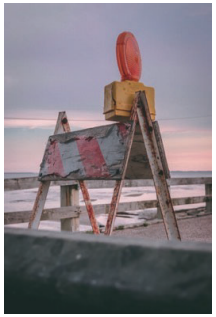
- Lack of communication and/or coordination between providers and/or systems
  - Lack of time
  - Lack of tools
  - Lack of resources to implement transition process



System Barriers

- Limited availability of adult primary and specialty care providers
  - Lack of time/assistance
  - Lack of matching systems

System Barriers



- Difficulty locating adult providers with specialized knowledge regarding pediatric onset conditions and community resources
  - Lack of transition training in residency, esp. internal medicine
  - Increased training opportunities (CME and MOC) needed for practicing clinicians

System Barriers

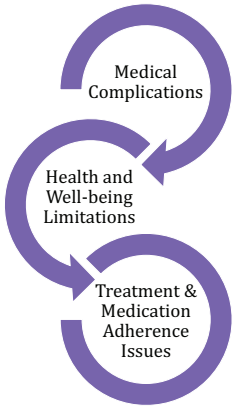
- Loss of insurance of young adults and costs of care
  - Service/therapy coverages may be age dependent
  - Eligibility changes
  - Coverage differences Medicaid to Medicare

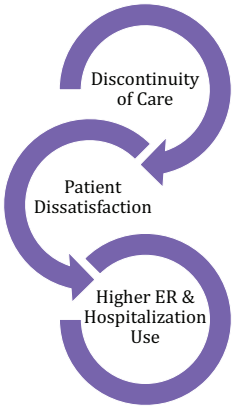
Consequences

"Special populations may not represent the majority of youth transitioning to adulthood, but in the aggregate, they include those must vulnerable to poor outcomes and higher health care costs."

-Pediatrics, 2018

Consequences





Consequences

Alphabet Soup!

IEP's!
IHP's!
ECP's!

WISCONSIN DEPARTMENT OF Public Instruction

Individualized Education Plan (IEP)

- An individualized education program (or IEP) is a written statement for a student with a disability that is developed, reviewed, and revised by a team of people, including the student's family, that outlines an educational plan for the student.

-https://dpi.wi.gov/families-students/student-success/ccr-iep

Documenting nursing services in the IEP

- Need for nursing services should be documented in the "present level of performance" and the "related services" section of the IEP
- Documentation in the IEP should include:
  - nursing services necessary to benefit from an education
  - consultation between the nurse (if 3rd party nursing services are utilized), school nurse, and teachers – document in the program modifications and support section of the IEP
  - the nurse's involvement in the student's educational program

https://dpi.wi.gov/sites/default/files/imce/sspw/pdf/snnursingservices.pdf

Individualized Health Plan (IHP)

- Document based on the healthcare needs of a student that impact or has the potential to impact
  - Learning or academic performance
  - Safe and optimal school attendance
- Based on the Nursing process!
- Should include student goals and expected outcomes with the goal of promoting health, preventing disease or injury, and enhancing academic achievement

https://dpi.wi.gov/sites/default/files/imce/sspw/pdf/wilyschoolnursesandplans.pdf
https://www.nasn.org/nasn-resources/professional-practice-documents/position-statements/ps-ihps

IHP's – Why Are They Important?

- Quality assurance documentation
- Foundation of health information needed to develop other school plans
- Enables essential, coordinated care and evaluation
- Promotes communication
- Provides quantifiable data about the outcomes that school nurses contribute to student success
- Documents evidence of our practice in accordance with professional standards

https://dpi.wi.gov/sites/default/files/imce/sspw/pdf/wilyschoolnursesandplans.pdf
https://www.nasn.org/nasn-resources/professional-practice-documents/position-statements/ps-ihps

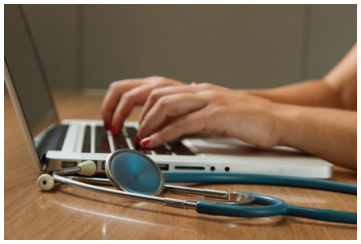
IHP's – Who Needs One?

- Students whose health care needs affect or have the potential to affect safe & optimal school attendance & academic performance
- Students with whom the nurse has multiple interactions (usually complex)
- Students with multiple health related absences

https://dpi.wi.gov/sites/default/files/imce/sspw/pdf/wilyschoolnursesandplans.pdf
https://www.nasn.org/nasn-resources/professional-practice-documents/position-statements/ps-ihps

Development of the IHP – It is just a care plan!

- Document baseline assessment necessary to measure outcomes (evaluation)
- Incorporate cultural and social perspectives
- Utilize the nursing process
  - Assessment
  - Nursing Diagnosis
  - Goals
  - Interventions
  - Expected outcomes



https://dpi.wi.gov/sites/default/files/imce/sspw/pdf/wilyschoolnursesandplans.pdf

IHP *in* the IEP?

- Including the IHP in the IEP is generally **NOT** recommended
  - IHP's may change frequently
  - Would need to reconvene or follow DPI guidelines for IEP revision with every change
  - Appropriate to **reference** the IHP in the IEP

https://dpi.wi.gov/sites/default/files/imce/sspw/pdf/wilyschoolnursesandplans.pdf

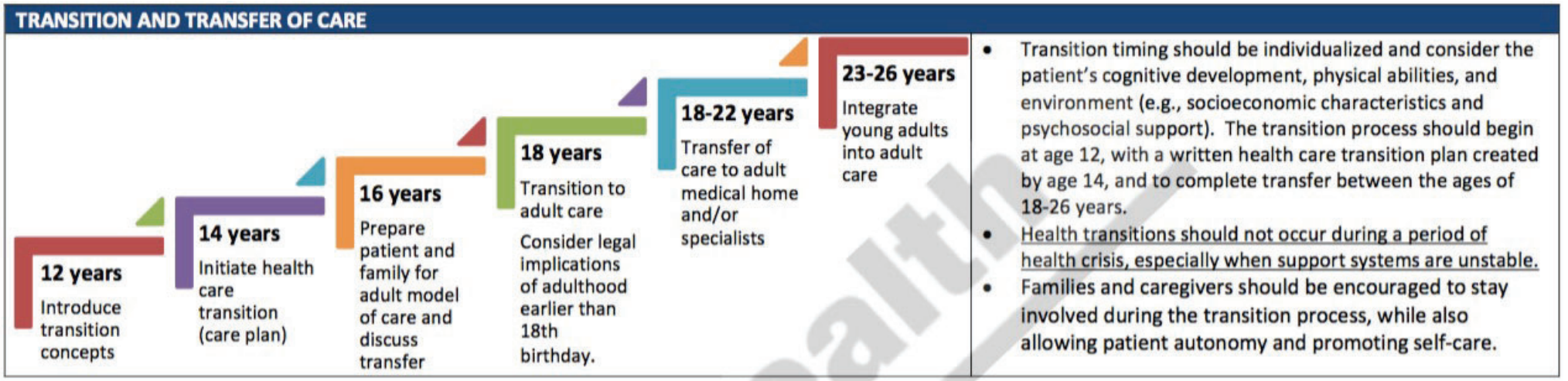
Emergency Care Plan (ECP)

- Plan for others to implement in school setting
- Written for lay person
- Focus on life threating illness that requires immediate response
  - Acute allergic reactions (Epi Pen)
  - Seizure
  - Hypoglycemia
- May reference in IEP, but would not be included

https://dpi.wi.gov/sites/default/files/imce/sspw/pdf/wilyschoolnursesandplans.pdf

Implementing a Youth Health Transition Process and the Role of the School Nurse

Transition Implementation Timeline



Transition related IHP Goal examples

2022: School nurse administering albuterol via inhaler
Photo source: Teresa DuChateau
https://www.wischoolnurses.org/a-day-in-the-life-home/past-and-present

- Assessment, education, and acquisition of health condition specific skills
  - Diabetes - Measuring blood sugar, calculating insulin doses
  - Asthma - Measuring peak flow, inhaler selection, administration of inhaler
  - Anaphylaxis allergies – recognizing triggers, recognizing symptoms, administering self treatments
  - Self care and acquisition of ADL skills

Got Transition

Develop Goals based on the Assessment
Got Transition has some sample goals to help you get started.

HCT READINESS ASSESSMENT ITEM	*SAMPLE GOAL*
MY HEALTH	
I can name my learning differences, disability, medical, or mental health diagnosis (e.g. diabetes, depression).	By the end of the IEP cycle, student will say aloud and/or spell out and/or enter into their cell phone the name(s) of their medical or mental health diagnosis(es), with __% accuracy.
I can name 2-3 people who can help with my learning differences, disability, medical, or mental health needs in an emergency.	By the end of the IEP cycle, student will input their emergency contacts' information on their phone and name and identify the contacts in their phone when asked, with __% accuracy.
Before a doctor's visit, I prepare questions to ask.	By the end of the IEP cycle, student will prepare and practice asking a few questions to their doctor before their next appointment, with __% accuracy.
I know to ask the doctor's office for accommodations, if needed.	By the end of the IEP cycle, student will identify which accommodations they need to request at a doctor's office, with __% accuracy.
I have a way to get to my doctor's office.	By the end of the IEP cycle, student will plan transportation to their doctor's office ahead of time, with __% accuracy.
I know the name(s) of my doctor(s).	By the end of the IEP cycle, student will input their doctor's contact information on their phone and name and identify their doctor in their phone when asked, with __% accuracy.

Got Transition Radio Episode 6 Transition and School Health & the Individual Education Plan IEP)

https://www.youtube.com/watch?v=6e3jjDx7KbE

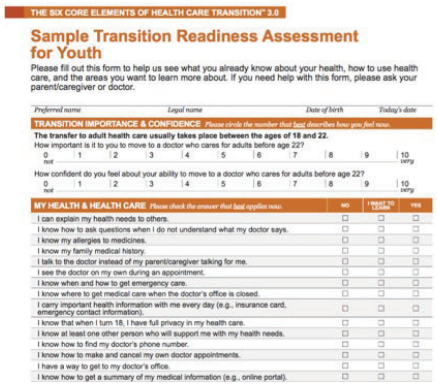
How Can School Nurses be a Part of Transition Planning?

https://www.youtube.com/watch?v=Nd_z0QAWx2w

March 22, 2023 Recording Resource Sheet Join Louise Wilson, Wisconsin Department of Public Instruction School Nurse Consultant, to talk about the overall role of school nurses and how they can be a critical part of successfully transition student from High School into adult life. Part of Conversations on Showing Up for Kids!

Transition Readiness Assessments - Tools for Assessing Student Related Health Transition Needs

GotTransition®



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?

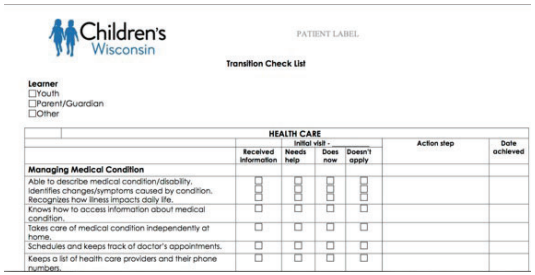
0 not | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 very

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 *Please check the answer that best applies now.*	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).	☐	☐	☐

Children's Wisconsin



Children's Wisconsin

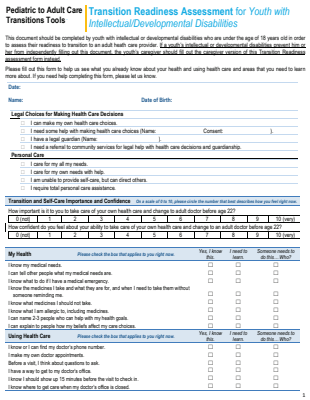
PATIENT LABEL

Transition Check List

Learner
☐Youth
☐Parent/Guardian
☐Other

HEALTH CARE	Initial visit - Received information	Needs help	Does now	Doesn't apply	Action step	Date achieved
Managing Medical Condition						
Able to describe medical condition/disability, identifies changes/symptoms caused by condition. Recognizes how illness impacts daily life.	☐ ☐	☐ ☐	☐ ☐	☐ ☐		
Knows how to access information about medical condition.	☐	☐	☐	☐		
Takes care of medical condition independently at home.	☐	☐	☐	☐		
Schedules and keeps track of doctor's appointments.	☐	☐	☐	☐		
Keeps a list of health care providers and their phone numbers.	☐	☐	☐	☐		

Transition Readiness Assessment for Youth with I/DD



Pediatric to Adult Care Transitions Tools | **Transition Readiness Assessment** *for Youth with Intellectual/Developmental Disabilities*

This document should be completed by youth with intellectual or developmental disabilities who are under the age of 18 years old in order to assess their readiness to transition to an adult health care provider. If a youth's intellectual or developmental disabilities prevent him or her from independently filling out this document, the youth's caregiver should fill out the caregiver version of this Transition Readiness assessment form instead.

Please fill out this form to help us see what you already know about your health and using health care and areas that you need to learn more about. If you need help completing this form, please let us know.

Date:

Name: Date of Birth:

Legal Choices for Making Health Care Decisions
- ☐ I can make my own health care choices.
- ☐ I need some help with making health care choices (Name: Consent:)
- ☐ I have a legal guardian (Name:)
- ☐ I need a referral to community services for legal help with health care decisions and guardianship.

Personal Care
- ☐ I care for my all my needs.
- ☐ I care for my own needs with help.
- ☐ I am unable to provide self-care, but can direct others.
- ☐ I require total personal care assistance.

Transition and Self-Care Importance and Confidence *On a scale of 0 to 10, please circle the number that best describes how you feel right now.*

How important is it to you to take care of your own health care and change to adult doctor 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 take care of your own health care and change to an adult doctor before age 22?

0 (not) | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 (very)

My Health *Please check the box that applies to you right now.*	Yes, I know this.	I need to learn.	Someone needs to do this... Who?
I know my medical needs.	☐	☐	☐
I can tell other people what my medical needs are.	☐	☐	☐
I know what to do if I have a medical emergency.	☐	☐	☐
I know the medicines I take and what they are for, and when I need to take them without someone reminding me.	☐	☐	☐
I know what medicines I should not take.	☐	☐	☐
I know what I am allergic to, including medicines.	☐	☐	☐
I can name 2-3 people who can help with my health goals.	☐	☐	☐
I can explain to people how my beliefs affect my care choices.	☐	☐	☐

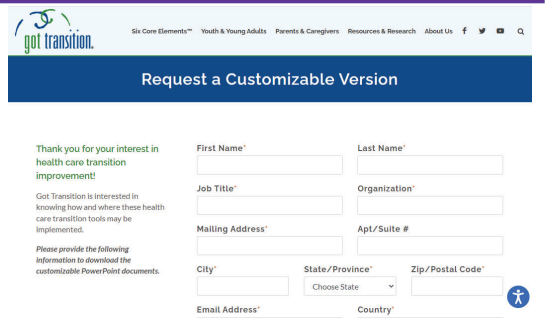
Using Health Care *Please check the box that applies to you right now.*	Yes, I know this.	I need to learn.	Someone needs to do this... Who?
I know or I can find my doctor's phone number.	☐	☐	☐
I make my own doctor appointments.	☐	☐	☐
Before a visit, I think about questions to ask.	☐	☐	☐
I have a way to get to my doctor's office.	☐	☐	☐
I know I should show up 15 minutes before the visit to check in.	☐	☐	☐
I know where to get care when my doctor's office is closed.	☐	☐	☐

- Word document of this assessment tool included with your handouts

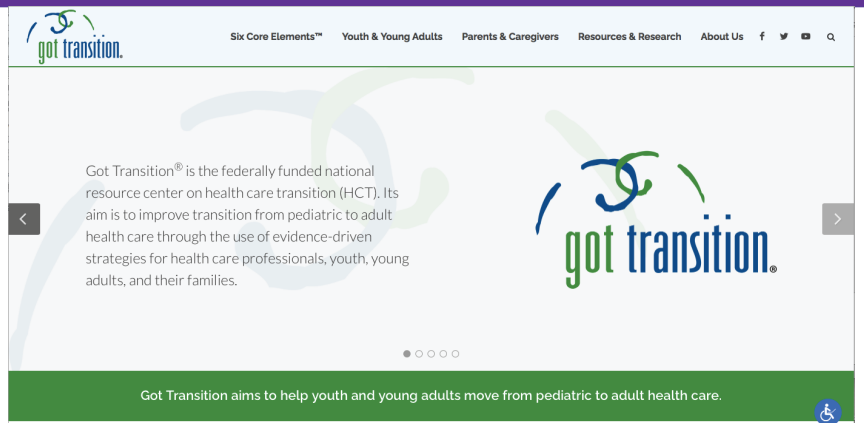
Customizing Got Transition® resources

- PDF's are customizable and downloadable
  - non-commercial use
  - requires attribution to Got Transition
  - Requires simple registry and then immediately available

https://www.gottransition.org/six-core- elements/request-customizable-version.cfm



Resources – GotTransition.org®



Resources – www.healthtransitionwi.org

Contact Information

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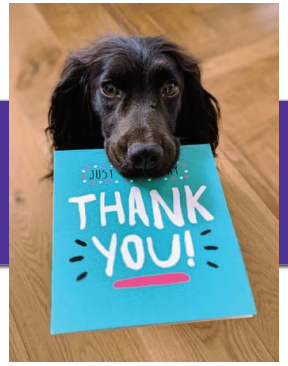
Wisconsin Youth Health Transition Initiative
Waisman Center, UW Madison

Did we meet your needs?

OR https://redcap.wisconsin.gov/surveys/?s=HHPPR93Y4A&sesson_name=5

Please select the "Provider Education: Youth Health Transition" option when submitting your session feedback. Please take the time to complete an evaluation on today's educational opportunity – that is how we maintain our funding to come to you today!



Thank you!

References

- White, PH, Cooley WC, TRANSITIONS CLINICAL REPORT AUTHORING GROUP, AMERICAN ACADEMY OF PEDIATRICS, AMERICAN ACADEMY OF FAMILY PHYSCIANS, AMERICAN COLLEGE OF PHYSICIANS. Supporting the Health Care Transition From Adolescence to Adulthood in the Medical Home. *Pediatrics.* 2018; 142(5):e20182587
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- Retrieved 4/7/23 - https://dpi.wi.gov/sites/default/files/imce/sspw/pdf/snnursingservices.pdf
- Retrieved 4/7/23 - https://dpi.wi.gov/sites/default/files/imce/sspw/pdf/wilyschoolnursesandplans.pdf