"Healthcare Transition for **Pediatric Patients** with Diabetes: **Getting READDY** at School"

> December 11th, 2024 DISH presentation M. Tracy Bekx, MD Victoria Nicksic, MD



What is Health Care Transition?

Health care transition, or HCT, is the process of moving from a child/family-centered model of health care to an adult/patient-centered model of health care, with or without transferring to a new clinician. It involves planning, transfer, and integration into adult-centered health care.

https://www.gottransition.org/six-core-elements/accessed 7.21.21





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Checking blood glucoses
Counting carbs
Dosing insulin
Treating highs/low
Filling prescriptions
Making appointments
Calling Diabetes Team
Driving and Diabetes
ETOH and Diabetes
Reproduction and Diabetes
Long term complications





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Why important to address Health Care Transition?

- Time of frequent lapses in care:
 - moving out of home
 - moving away from "medical home"
 - moving to an adult provider/new team

Diabetes Care, Vol 38, January 2015 Diabetes Care 2011 Nov; 34(11): 2477-2485

Diabetes. 2021;70(Supplement_1). doi:10.2337/db21-833-P



Time of Emerging Stresses:

- Erratic eating patterns-work, school
- Time constraints: work, school, relationships
- Finances/Food/insurance
- Absence of social support-changes in relationships
- Mental health
- Alcohol



Time of Emerging Chronic Complications

Studies looking at young adults ages 18-30 years

• Retinopathy: 12%-20%

• Nephropathy: 7.3-14.8%

• Hypertension: 30-33%

Neuropathy: 8.2% of teens+

James et al, BMC Research Notes, 2014: 7:593

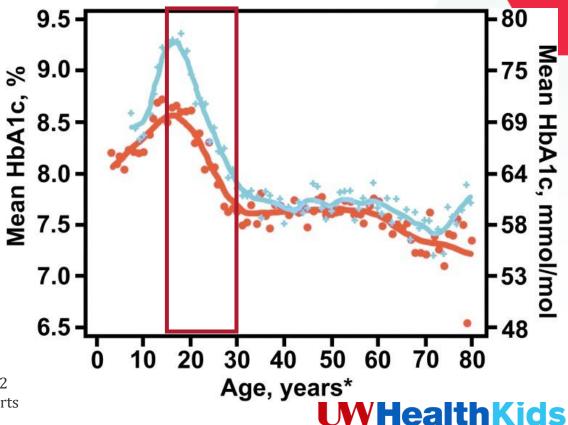
Jaiswal et
SEARCH Study, Diabetes Care, 2013
WHealthKids

Issues in Transition

Suboptimal health care utilization due to change in health

care delivery model

Risk for poor glycemic outcomes



Average HbA1c by year of age: 2010–2012 versus 2016–2018. Orange line represents 2010–2012 cohort, and blue line represents 2016–2018 cohort. Participants must be contained in both cohorts with at least a 3-year duration for the 2010–2012 collection. * \geq 80 years old are pooled.

Why important to address: ADA guidelines

"Pediatric health care providers, working collaboratively with the
patient and family, should prepare the developing teen for the
upcoming transition in health care delivery beginning at least 1 year
prior to the transfer to adult health care providers, and likely during
the early adolescent years."

• "Preparation should include a <u>more directed focus on diabetes self-management skills</u> for the teen/emerging adult and his/her parents"



When to start the Transition Process?

- American Academy of Pediatrics (AAP) suggest that transition planning should begin as early as age 14, including regular assessments to identify self-care needs and goals
- AFCH: Can start as early as age 8-10 years
- ? At diagnosis?



How to carry out Transition



IDENTIFYING TOOLS FOR ASSESSMENT

FINDING TIME AND OPPORTUNITY TO IMPLEMENT



Tools for Transition Specific to Diabetes:

- Endocrine Society Transition Assessment
- READDY—Dr Nicksic



Endocrine Society Transition Assessment

KNOW

Basic knowledge of your diabetes: □ Type 1 □ Type 2 ☐ Other Forms Describe what insulin does ☐ If you take oral medications, describe how they keep blood glucose in range ☐ Describe what happens if you don't take your medications ☐ Describe the meaning of HbA1c Describe the link between HbA1c level and the risk of diabetes complications ☐ Describe how nutrition/diet affects blood glucose and cardiovascular (heart and blood vessel) health ☐ Describe the effect of exercise on blood glucose (right after exercising and overnight) Describe how to drive safely ☐ Describe how to drink alcohol responsibly and reduce risk of low blood glucose levels □ Describe importance of excellent blood glucose control before & during pregnancy to support the development of a healthy baby ☐ Describe risk for other autoimmune diseases and symptoms to look for (for type 1 patients) ☐ Describe the need for and recommended frequency of routine check-ups ☐ Describe the need for annual lab work to assess kidney, eye, and cardiovascular health Describe the need for routine dental care exams



Experience in the following skills: ☐ Accurately measure and give yourself insulin injections (even if you're on insulin pump therapy) □ Calculate correct dose of insulin according to both blood glucose level and carbohydrate intake ☐ Monitor blood glucose □ Monitor ketone levels (urine or blood) during illness, stressful times or when blood glucose levels are persistently elevated Log or download blood glucose readings □ Be able to state target blood glucose levels/range and goal HbA1c level Show how to program date/time into blood glucose meter and any other devices you may use □ Be able to count/estimate carbohydrates ☐ For those on fixed dosing, state number of carbohydrates to eat at each meal/snack □ Describe the reasons for changing/rotating injection/infusion sites Wear a medical alert identification



For those on insulin pump therapy/continuous glucose meter: Demonstrate how to insert infusion set Demonstrate how to check diabetes supplies and when it's time to order new supplies Demonstrate how to access insulin pump basal and bolus settings and how to alter them Demonstrate how to download pump/glucose monitor information Demonstrate how to share pump/glucose monitor information with the diabetes care provide Demonstrate how to program the pump (date, time, correction dose, carb dose, insulin on board, types of boluses, basal rates and temporary basal rates) Demonstrate when to use insulin injections and monitor for ketones to prevent diabetic ketoacidosis (DKA)



Show ability to arrange for medical care:

NAVIGATE

- Be able to make appointment
 - ☐ Identify what insurance you have now.
 - □ Identify what insurance you will have when you are over 18 years of age
 - □ Be able to keep track of insurance claims and co-pays
 - Be able to maintain prescriptions and obtain medications/supplies before you run out
 - ☐ Identify the name and phone number of pediatric endocrinologist
 - ☐ Identify the name, phone number, and office location of adult endocrinologist
- Confirm contact information for urgent issues after office hours, weekends, holidays



Resources—on Transition and Transfer of Care-Moving into Adulting Breakthrough T1D (formally JDRF)

Transitioning to Independence

A Guide for Young Adults with T1D



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Transitioning Tips

- Before you transition to an adult endocrinologist, practice taking charge of your
 endocrinology appointments. For example, you could come prepared with a list of
 questions you would like your doctor to answer, and when your doctor asks how things
 are going, try responding before your parent or guardian responds! See more tips here
 for effective communication with doctors.
- Try to begin the transition process as early as possible. For example, in early
 adolescence, parents/guardians can gradually begin transitioning diabetes management
 tasks to the adolescent. At least one year before transferring to adult care, ask your
 pediatric endocrinologist for an adult endocrinologist referral to ensure no gaps in your
 care.
- If possible, transfer to an adult primary care provider before you transfer to an adult endocrinologist. It's best not to transfer to two new doctors at the same time!



Academics

Work with the Accommodations Office or Disability Services to request any accommodations you feel you need, including:

- Extended exam time / rescheduling
- Ability to take food into exams
- Meal plan flexibility
- (See a full list in the College Accommodations section)
- If comfortable doing so, email your professors prior to class (depending on your school's policy) to inform them you have T1D.
- Keep extra low snacks and glucagon with you at all times.
- Familiarize yourself with the campus and learn where your classes are located and determine how far you will need to walk before classes begin.

Drinking Responsibly

Guiding Principles

- Drinking alcohol in excess increases the risk of hypoglycemia.
- It's best to avoid drinking large amounts of alcohol in one session.
- Make sure you always have some carbohydrates to eat before you drink.
- It's recommended that you don't include the carbohydrate content of alcohol in your carbcounting calculations. You should aim to eat some carbohydrates every few hours as you continue to drink.



- Be sure to stay adequately hydrated by drinking plenty of water.
- Test your blood glucose levels before you go to bed and if your level is normal to low, eat a snack before you head to sleep.
- Be very cautious about lows the night after drinking, have a low snack prepared for a sudden drop in glucose levels while sleeping.
- Closely monitor your blood sugar the next day as alcohol can cause you to go low hours after consumption.

Sources / Additional Resources

- JDRF: What You Need to Know About Type 1 Diabetes and Alcohol
- JDRF: Alcohol and Type 1 Diabetes: How to Manage A Night Out and the Moming After
- American Diabetes Association: Alcohol and Diabetes



ALL THINGS COLLEGE

I AM...

experts.

A lot of our learning at The Diabetes Link comes from listening to YOU - the person living with the diagnosis. If you've got something you want to know more about, or a resource to share that was really helpful to you - let us know!

Check these out (aka educate yourself!):







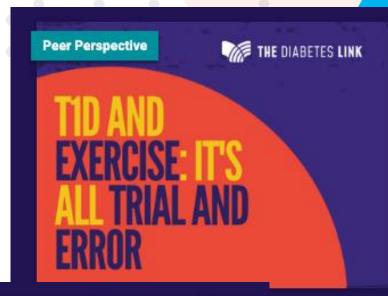














Empower Yourself!



Role of School RNS and Transition

- Frequent interaction with students, sometimes daily
- School orders-opportunity for discussion
- Develop a system of Transition Assessment and education through the school



Getting READDY at School:

Collaborating with School Nurses for Diabetes Transition Success



Getting READDY at School Goal

Implement a <u>school-based</u> diabetes transition readiness assessment using the READDY survey



READDY TEAM MEMBERS

- School-based team
 - Nurse Coach & Lead Nurse
 - Middle & high school nurses
- UW team
 - Dr. Tracy Bekx Director of the Pediatric Diabetes Program
 - Dr. Victoria Nicksic Third year Fellow in Pediatric Endocrinology
 - Whitney Beaton, MSN, RN, ACCNS-P, CDCES.
- Transition Resource Team
 - Tim Markle MA; MA/CS, Program Manager Wisconsin Youth Health Transition Initiative



What is the READDY survey?

Readiness for Emerging Adults with Diabetes Diagnosed in Youth (READDY)

"Tool is designed to assess <u>self-reported</u> confidence levels on diabetes-specific health knowledge and skills. In this framework, higher confidence in one's ability to perform health-related skills indicates a higher level of readiness for transition. A Likert reporting scale enables clinicians to identify priority topics for <u>educational</u> interventions and follow changes in responses over time."



46 question survey focusing on diabetes knowledge, navigation, insulin management, health behaviors and pump skills

READDY- V1.1 for distribution

Name:

DOB:

How ready are you for transition to adult diabetes care?

Date:

Transition Readiness assessment for Emerging Adults with Diabetes Diagnosed in Youth

Listed below are some knowledge or skill items that are useful in keeping you healthy with diabetes over your lifetime. This is not a test. There are not right or wrong answers. Please try to answer honestly. Be sure to ask your provider if you need more help in any of these areas.

Knowing the facts about diabetes (Knowledge)	Yes,	Somewhat,	No, I still	I plan to start	Haven't
I am able to:	I can do this	but I need a little practice	needs lots of practice		thought about it
Describe diabetes in my own words					
Explain what Hemoglobin A1c (HbA1c) measures					



2023-2024 School Year PILOT—Is this feasible?

School RNs deployed a <u>truncated 5 question</u> READDY survey to MS and HS students in fall and spring semester

9 school nurses participated

- 3 middle schools: 14 students with diabetes
- 5 high schools: 20 students with diabetes

100% of MS students from participating schools completed survey

67% of HS students from participating schools completed survey

l am able to...

Test blood glucose before each meal and when having symptoms of low glucose values

Count Carbs, where to look for carb information, and determine insulin dose based on carbs

Determine insulin dose based on blood glucose

Respond to positive ketones

Teach a friend about treatment/signs for hypoglycemia



2023-2024 Results & Feedback

- More middle school than high school students participated
- Many HS students felt confident in 5 skills included on the truncated survey
- School RNs asked for clinic approved interventions
- Most student and nurse participants felt this was useful and feasible



2024-25 School Year - How can we EXPAND?

Increase participation rate of MS and HS students completing a READDY survey

Include more school nurses \rightarrow include more schools \rightarrow expand to more students with diabetes



2024-25 School Year - How can we include more SCHOOL NURSES?

Utilize coach FNP

Expand project promotion and advertisement

Nurse compensation



2024-25 School Year – How can we include more STUDENTS?

- Increase student buy-in
 - Learning topic
 - Student compensation



2024-25 School Year - Other changes

Expand READDY survey

- HS Full length
- MS ~50%

Include learning topic to focus

Development of educational resources for the school RNs to sha

Diabetes Survey Project 2024/25 SY for Middle &

High School students

"Readiness for Emerging Adults with Diabetes Diagnosed in Youth (READDY), is a tool is designed to assess <u>self-reported</u> confidence levels on diabetes-specific health knowledge and skills. In this framework, higher confidence in one's ability to perform health-related skills indicates a higher level of readiness for transition. A Likert reporting scale enables clinicians to identify priority topics for educational interventions and follow changes in responses over time."

September to October 18th: Have students complete the READDY survey, including selecting one learning topic, and return to Laurel or fill out the appropriate google form.

- Middle School Survey Google Form
- High School Survey Good Form

First Semester: As able, use time to review with student learning topic, utilizing the resources below as needed.

February to March 10th, 2025: Students to complete a post survey, addressing the learning topic and impact of the READDY survey. School RNS to complete a post survey for feedback. Return to Laurel

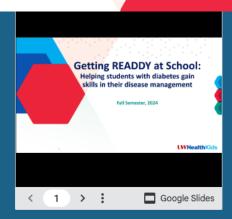
Parent/Guardian letter English

Parent/Guardian letter Spanish

Building admin letter

Education Resources:

- UW Diabetes Resources for School Nurse
- UW Health Kids & Schools Pediatric Diabetes Curriculur
- Powerpoin



High School Surveys

- ENGLISH
- SPANISH

Middle School Surveys

- ENGLISH
- SPANISH



2024-25 School Year – How are we doing so far?

- 16 school nurses participating
 - 6 middle schools → 20 students with diabetes
 - 7 high schools → 33 students with diabetes

- 92% of MS students from participating schools completed survey
- 67% of HS students from participating schools completed survey

 I W Health Kids

2024-25 School Year - What's next?

- Spring semester post-survey
 - Was the learning topic helpful?
 - Did students and nurses access clinic-provided resources?
 - What type of resources do students desire?



Future goals

- Does this help with glycemic control?
- Can we expand this further?
 - More school systems
- Should we start this earlier?
 - Elementary schoolers?





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Treating highs/low
Filling prescriptions
Making appointments
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ETOH and Diabetes
Reproduction and Diabetes
Long term complications

School Nurses
Diabetes team members
Educational resources
Community/Support
Family /Friends



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Other Resources

https://healthtransitionwi.org/wisconsin-school-nurses/#resources-school-nurses





Home

Families & Youth

Providers

Wisconsin School Nurses

Health

Home / Wisconsin School Nurses

Wisconsin School Nurses

Healthcare Transition is the change from pediatric to adult healthcare services. This transition typically takes place between the ages of 12 and 26 years. This webpage offers tools, resources, and trainings to help Wisconsin School Nurses provide best practice transition care to their patients with developmental disabilities or special healthcare needs.



READDY SURVEY sample questions

Taking care of diabetes on my own (Navigation)	Yes, Lean do this	Somewhat, but I need a	No, I still needs lots of	I plan to start	Haven't thought
I am able to:	rean do tino	little practice	practice		about it
Arrange for transportation to medical appointments					
Ask questions of the medical team during my clinic visit					
Answer questions about my own past health history					
Answer questions about my family medical history					
Call the office for treatment advice					
Have medical insurance or speak to a social worker or financial					
counselor about getting coverage Call my insurance company and ask about my coverage for supplies and medicines					
Refill a prescription at the pharmacy					
Seek emotional support as needed (family, friends, online community, religious services, social worker, support group, therapist, etc)					
Identify a hospital for emergency care					
Identify a primary care provider (one main health care provider I see for all my medical needs other than diabetes)					
Contact prospective schools and employers for disability accommodations (if necessary)					
Find out accurate information about diabetes (through support groups, websites, ADA, JDRF etc.)					
Insulin/Diabetes Management Skills (Insulin Management) I am able to:	Yes, I can do this	Somewhat, but I need a little practice	No, I still needs lots of practice	I plan to start	Haven't thought about it
Give my own insulin with a syringe, pen or pump					
Determine my insulin dose according to my blood glucose					
Determine my insulin dose according to what I am eating					
Adjust my insulin doses according to my blood glucose patterns over time					



Are you interested in learning more?

• Please email mtbekx@wisc.edu and diabetesinschoolhealth@gmail.com.

