NTACT THE COLLABORATIVE

Bridging the Gap: Supporting Healthcare Transitions for Students with Disabilities

Panel Presentation

April 3, 2025

Welcome

Webinar Logistics

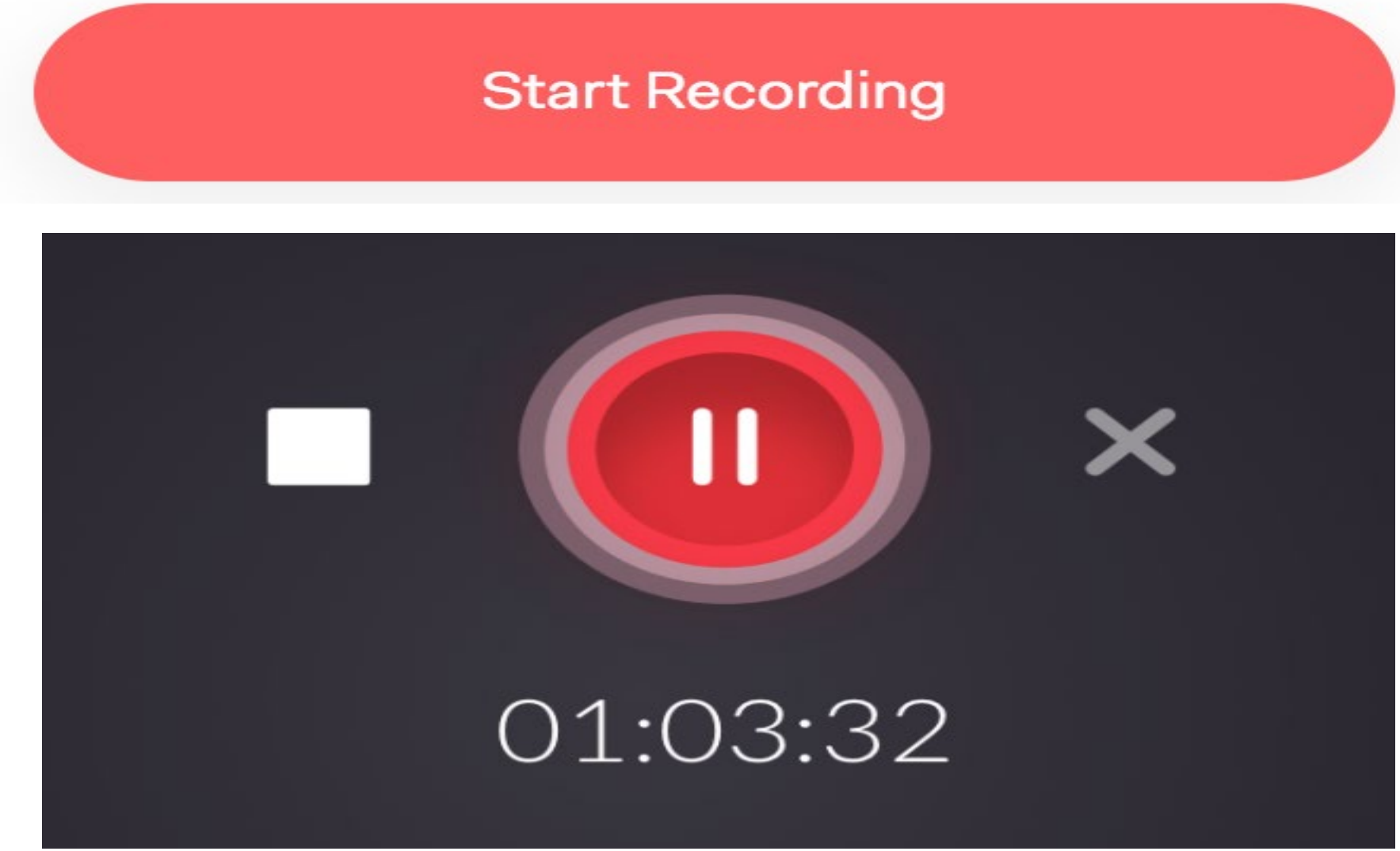
- You are muted throughout today's presentation
- The PowerPoint for today's session along with the session evaluation and webinar recording will be available on the NTACT:C website under Training or directly @ https://transitionta.org/trainings/supporting-healthcare-transitions
- If you haven't done so already, please register for our website and login
- AI notetaking bots will be removed from meeting to maintain confidentiality and accuracy of information shared.

How to Engage in Today's Discussion

Use the **CHAT** feature

1. Find Chat at **top left of the screen**
2. Click **Chat**
3. Type your question or comment

Today's Discussion will be Recorded



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Bridging the Gap: Supporting Healthcare Transitions for Students with Disabilities(2)

Panel Presentation

April 3, 2025

Today's Agenda

- Introduction of panelists & why this presentation
- Overview of Healthcare Transitions for Students with Disabilities
- Effective Practice Strategy – Video Story Telling
- A Family Member's Perspective of Healthcare Transitions
- A Young Adult Perspective of Healthcare Transitions
- Importance of Engaging School Nurses in Healthcare Transitions
- Incorporating Healthcare Transitions in Secondary-Transition
- Final Tips and Takeaways

Meet the Panelists

- **Karen Benson** - Karen Benson is the Health and Education Program Manager with Oregon Center for Children and Youth with Special Health Needs
- **Lydia Dennehy** - Lydia Dennehy is a Resource Specialist and Parent Partner with Oregon Family to Family Health Information Center
- **Shelia Harris** – Family member
- **Samhita Ilango** – Samhita Ilango is a senior research/policy associate for the National Alliance to Advance Adolescent Health/Got Transition

Meet the Panelists (2)

- **Tim Markle -** Director of the Wisconsin Youth Health Transition Initiative
- **Peggy McManus** – President of The National Alliance to Advance Adolescent Health/Got Transition
- **Michael Stoehr** -Knowledge Development and Technical Assistance Specialist with the National Technical Assistance Center on Transition: the Collaborative (NTACT:C)
- **Elizabeth Stout** – Young Adult – YETI Member

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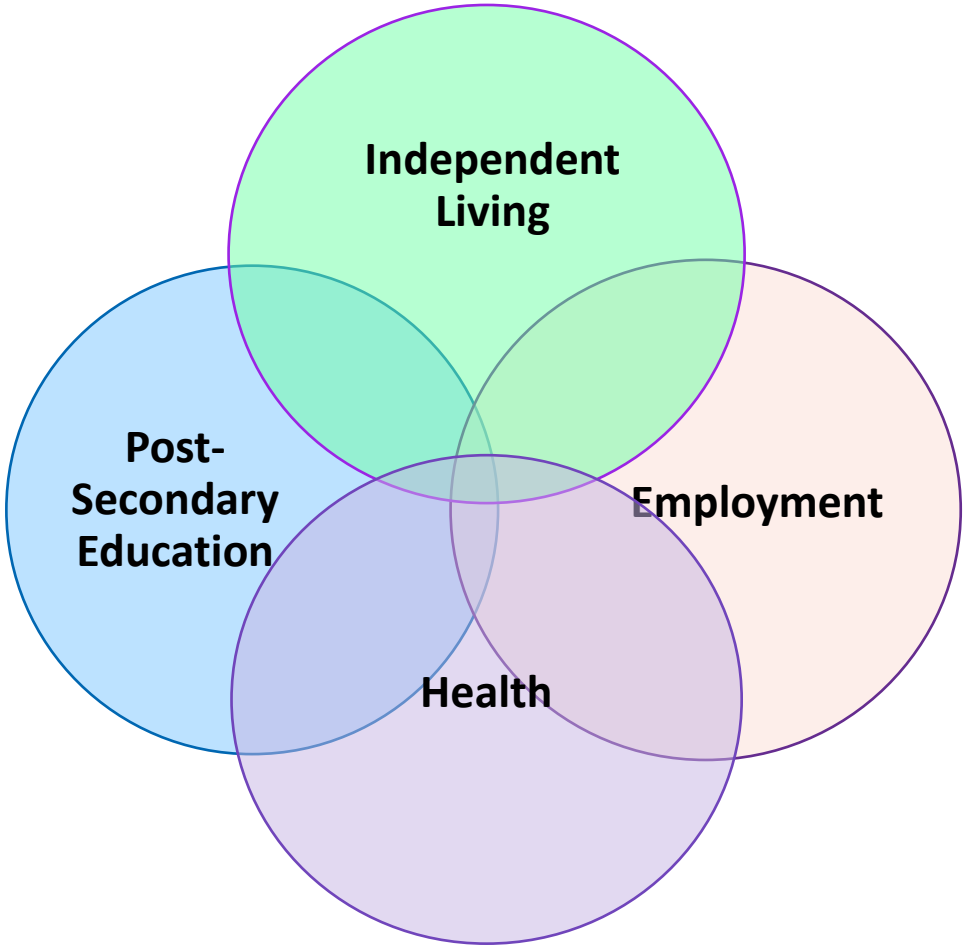
Overview of Health Care Transition for Students with Disabilities

What is Health Care Transition?

- Health care transition, or HCT, is the process of getting ready for health care as an adult.
- The goal is to improve the ability of youth or young adults to manage their own health and health care and effectively use health services

The Importance of HCT Planning

- HCT is important in areas of post-secondary education, employment, and independent living.
- However, little attention has been directed at helping students learn about their own health needs and medicines, how best to manage their own health, how to use health care, and how to plan for transfer to adult health care.



Got Transition Resources to Support Incorporating HCT in Special Education

Check out this page on GotTransition.org

Special Education

- Disabilities, Opportunities, Internetworking, and Technology (DO-IT)
- Institute for Educational Leadership (IEL)
- National Resources for Advocacy, Independence, Self-determination, and Employment Technical Assistance Center (RAISE)
- National Technical Assistance Center on Transition (NTACT)
- Postsecondary Education *from PACER's National Parent Center on Transition and Employment*

Got Transition Resources

- Health Care Transition Readiness Assessment for use in the Individualized Education Program (English) *with funding from DC Health*
- Health Care Transition Readiness Assessment for use in the Individualized Education Program (Spanish) *with funding from DC Health*
- Sample Goals for the Health Care Transition Readiness Assessment for Students with an Individualized Education Program *with funding from DC Health*
- Health Care Transition Skills Checklist *in partnership with the Parent Educational Advocacy Training Center*
- Customizable Tip Sheet: Improving the Health of Students in [State] Through Health Care Transition

Got Transition Tools

Got Transition, in partnership with DC's Community of Practice on Secondary Transition and with extensive input from special educators, city officials, and families, created the following two tools for students with an IEP and special educators:

1. *Health Care Transition Readiness Assessment*
    - Completion of Got Transition's Health Care Transition Readiness Assessment for Students with an IEP will reveal student knowledge about their health and using health care and areas they need to learn more about.
2. *Health Care Transition Sample Goals*
    - Practical, achievable, and measurable sample goals based on the results of the assessment can be used by IEP team to develop transition plan goals.

Health Care Transition Readiness Assessment for Students with an IEP

Health Care Transition Assessment

Pediatric to Adult Health Care Transition Tool | **Health Care Transition Readiness Assessment** *for Students*

This health care transition readiness assessment is intended for students and their family/caregivers to compete as part of IEP transition planning meetings. If a student is unable to fill out this form, the student can complete it with the help of their family/caregiver.

Directions: Please check the box next to the answer that best applies to you right now. This helps us see what you already know about your health and using health care and areas that you need to learn more about.

Student Name: Student Date of Birth:

Completed By: Date Completed:

Personal Care *(related to dressing, eating, bathing, and moving)*	**Use of Communication Supports**
☐ I am able to care for all my needs	☐ Text-to-speech technology
☐ I need a little bit of help to care for my needs	☐ Assistive Listening Systems
☐ I need a lot of help to care for my needs	☐ ASL/Interpretation technology
☐ I need help to care for all my needs	☐ Other technology:
	☐ I do not use communication supports

Transition Importance & Confidence *On a scale of 0 to 10, please circle the number that best describes how you feel right now.*
**The transition to a doctor who cares for adults usually occurs between ages 18-22.*

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

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

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

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

My Health *Please check the box that applies to you right now.*	**Yes**	**I want to learn**	**No**
I can name my learning differences, disability, medical, or mental health diagnosis (e.g. diabetes, depression).	☐	☐	☐
I can name 2-3 people who can help me with my intellectual differences, disability, medical, or mental health needs in an emergency.	☐	☐	☐
Before a doctor's visit, I prepare questions to ask.	☐	☐	☐
I know to ask the doctor's office for accommodations, if needed.	☐	☐	☐
I have a way to get to my doctor's office.	☐	☐	☐
I know the name(s) of my doctor(s).	☐	☐	☐
I know or I can find my doctor's phone number.	☐	☐	☐
I know how to make my doctor's appointments.	☐	☐	☐
I carry my health information with me every day (e.g. insurance card, emergency phone numbers).	☐	☐	☐
I know my food allergies.	☐	☐	☐

My Medicines *Please check the box that applies to you right now.*	**Yes**	**I want to learn**	**No**
I know the name of the medicines I take.	☐	☐	☐
I know the amount of the medicines I take.	☐	☐	☐
I know when I need to take my medicines.	☐	☐	☐
I know how to read and follow the direction labels on my medicines.	☐	☐	☐
I know what to do when I run out of my medicines.	☐	☐	☐
I know my medicine allergies.	☐	☐	☐

Sample Goals for the HCT Readiness Assessment for Students with an IEP

[Sample Goals Webpage]

Sample Goals for the Health Care Transition Readiness Assessment for Students with an IEP

If a student has responded "No" or "I want to learn" to any of the items on the Health Care Transition Readiness Assessment, please use the following sample goals as a guide when creating goals in the IEP transition plan.

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 intellectual 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.
I know or I can find my doctor's phone number.	By the end of the IEP cycle, student will name and identify their doctor in their phone when asked, with __% accuracy.
I know how to make my doctor's appointments.	By the end of the IEP cycle, student will know how to call their doctor's office or use an online portal to schedule a future appointment, with __% accuracy.
I carry my health information with me every day (e.g. insurance card, emergency phone numbers).	By the end of the IEP cycle, student will keep their insurance card safely in their wallet/backpack or take a photo of it and store it on their phone and be able to retrieve the insurance card when asked, with __% accuracy.
I know my food allergies.	By the end of the IEP cycle, student will be able to say aloud and/or spell out and/or enter into their cell phone the name(s) of the foods they are allergic to, with __% accuracy.

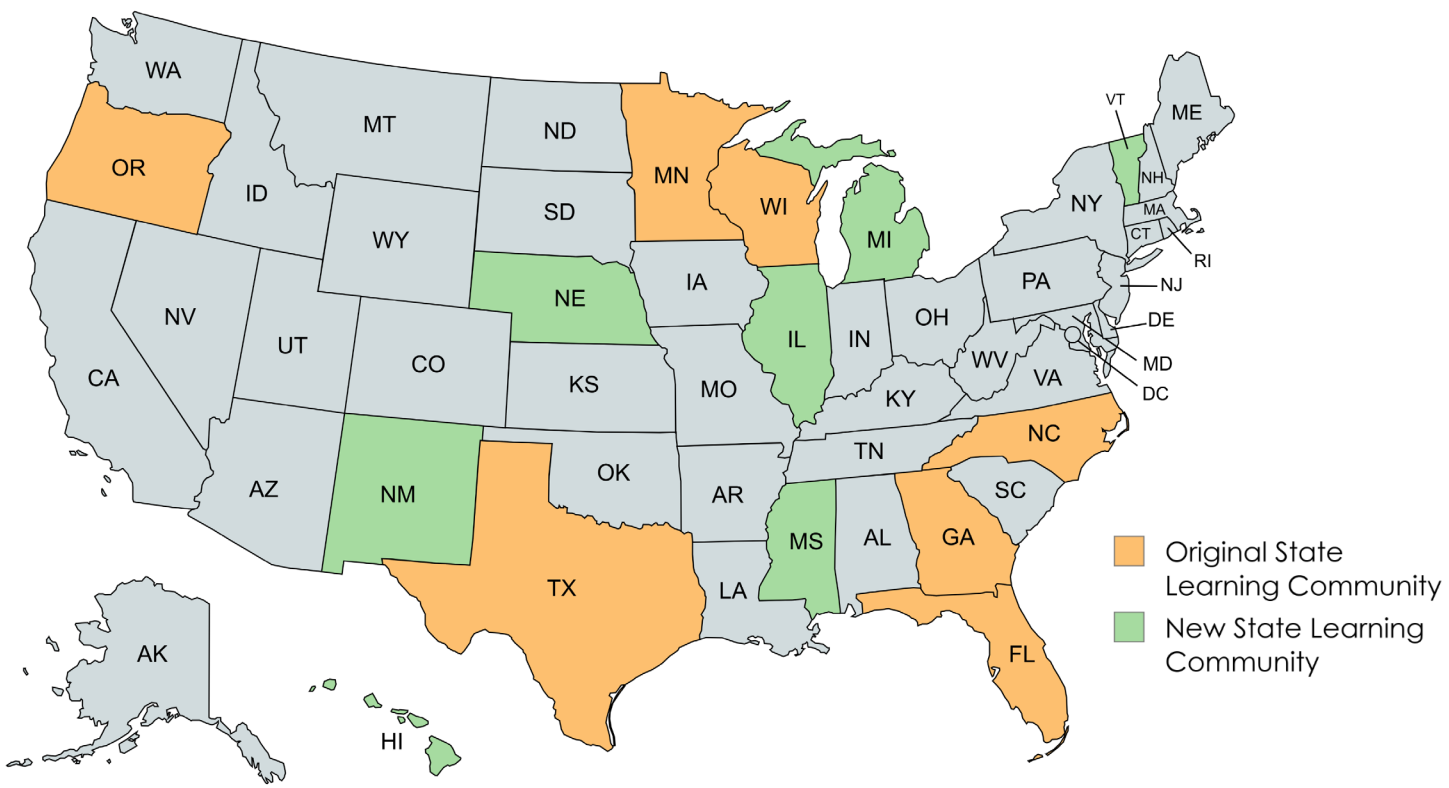
Sample Goals for the HCT Readiness Assessment for Students with an IEP

Sample Goals for the Health Care Transition Readiness Assessment for Students with an IEP

HCT READINESS ASSESSMENT ITEM	*SAMPLE GOAL*
MY MEDICINES	
I know the name of the medicines I take.	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 medicines, with __% accuracy.
I know the amount of the medicines I take.	By the end of the IEP cycle, student will say aloud and/or spell out and/or enter into their cell phone the dosages of their medicines, with __% accuracy.
I know when I need to take my medicines.	By the end of the IEP cycle, student will identify at what time to take their medicines, with __ % accuracy.
I know how to read and follow the direction labels on my medicines.	By the end of the IEP cycle, student will identify, read, and follow the directions on their medicines, with __ % accuracy.
I know what to do when I run out of my medicines.	By the end of the IEP cycle, student will call their doctor's office or pharmacy to ask about medication refills, with __ % accuracy.
I know my medicine allergies.	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 the medicines they are allergic to, with __% accuracy.

Special Education and HCT Multi-State Learning Communities

- Got Transition has convened states in learning communities to elevate the importance of HCT planning for students with disabilities.
- In 2022, the original 8 states formed the first learning community (**FL, GA, MN, NM, NC, OR, TX, WI**)
- In 2025, a new wave of states and territory joined the second learning community (**HI, IL, MI, MS, NE, NM, MP, VT**)



Effective Practice Strategy – Video Story Telling

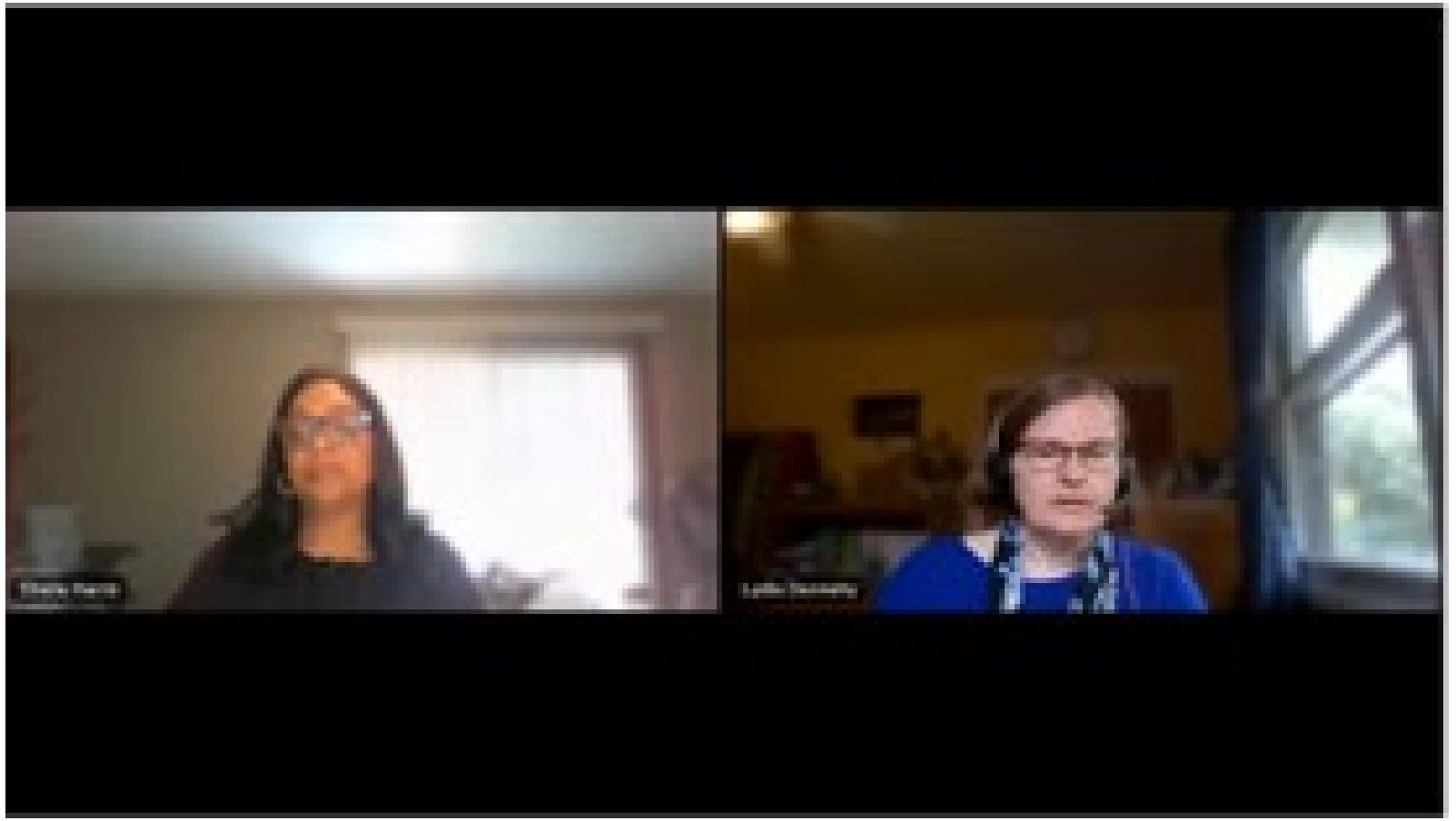
Why use video story telling

- To frame discussions about youth with special health care needs
- To illustrate the importance of cross-systems care coordination
- To allow families to tell their story in a less stressful situation
- To allow professionals to think and reflect when hearing stories

Tips for video story telling

- Have a strong relationship with the interviewee
- Gain informed consent
- Establish a clear goal and focus for interview
- Share and practice questions ahead of time
- Make use of editing software

Video Story Telling Clip



A Family Member's Perspective of Healthcare Transitions

Shelia Harris's Perspective

- What are you doing now with your daughter's school, doctors, and other helpers to make sure she got the support she needs both now and as she moves on to adult life?
- What things helped the most?
- What things have been a struggle?
- What advice would you give to other families going through the same thing?

Young Adult Perspective

Elizabeth Stout's Perspective

- Looking back at your high school and college experience, what support or resources helped you the most with transitioning to adult healthcare and managing your education and health needs?
- If you could change anything about how your healthcare and education transition was handled, what would it be?
- What advice would you give to other young adults with special healthcare needs as they prepare for life after high school?

Youth: Self Knowledge

- Brief health history
- Diagnosis
- Allergies
- Basic knowledge of diagnosis
- Physician
- Medications and dosage
- Insurance information

Youth: Self Advocacy

- Start early
- Gradual assumption of responsibility
- Correct information about health
- Physician, parents and healthcare staff must all support the self advocacy

Importance of Engaging School Nurses in Healthcare Transitions

Engaging School Nurses

- Recognize the unique skill set – Health and Education
- Get involved in IEPs and Transition Planning
- Talk with students about how to ask their doctor questions
- Help students learn to describe their symptoms
- Help students learn to fill prescriptions and take medications
- Consider any health plans or emergency care plans that may need to move forward with the student after exiting school

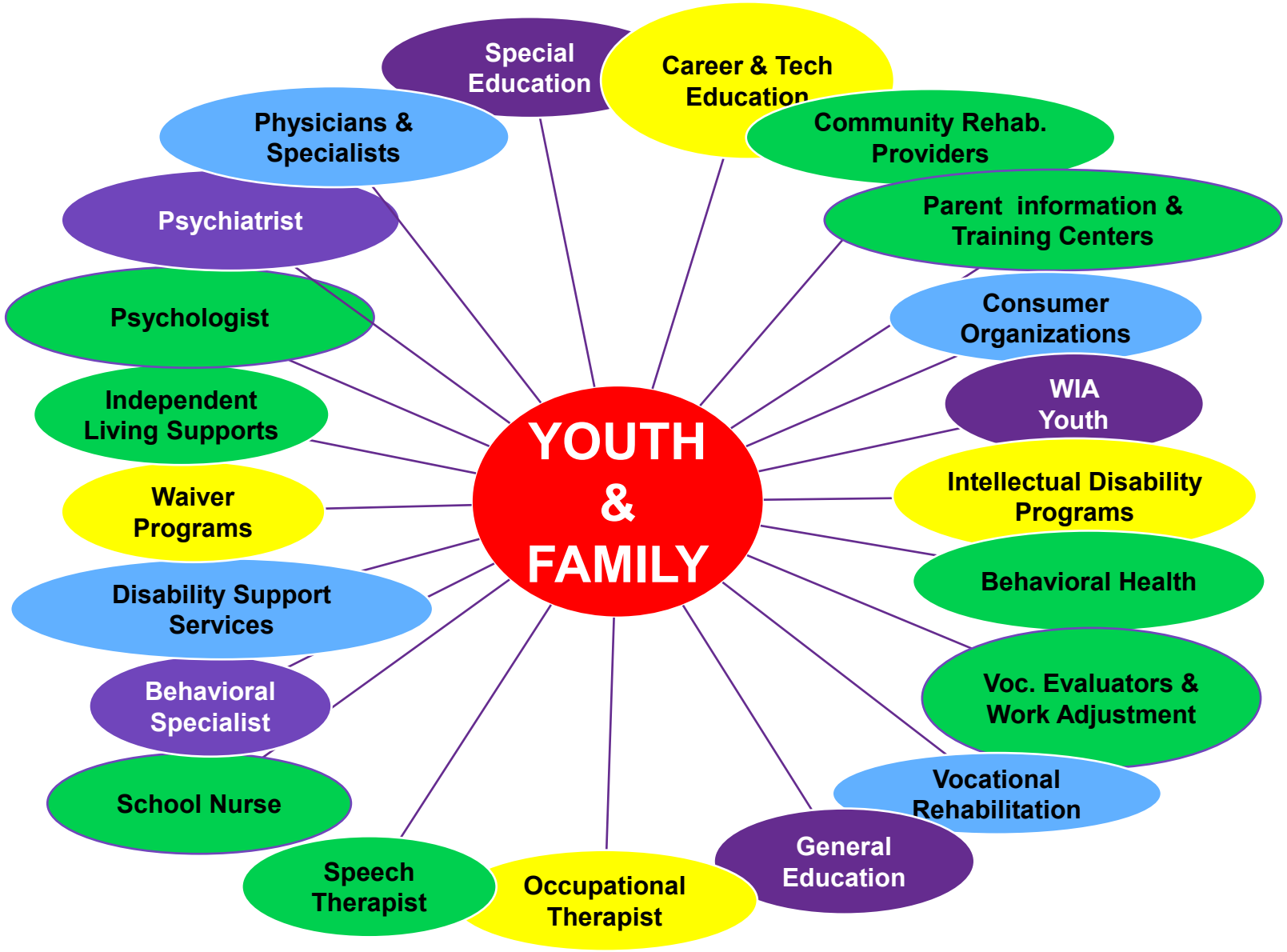
Engaging School Nurses (2)

- Make a website: https://healthtransitionwi.org/wisconsin-school-nurses/
  - Include their resources
  - Add an information sheet in partnership with Got Transition
- Do some videos: https://www.youtube.com/channel/UCI2Y6aN0RiUCJA8BHaytlRA
- Write articles for their newsletter
- Exhibit and/or present at their conferences
- Provide Technical Assistance for Quality Improvement project around Diabetes

Incorporating Healthcare Transitions in Secondary-Transition

Multi-professional Silos of Transitions

Transition Team Partners



Moving Towards an Interprofessional Mindset

Definitions

Multi-professional

- Shared experiences
- No expectation of interaction or participative decision-making

Interprofessional

- Shared experiences
- Interaction/joint decision making
- Shared responsibility/ accountability for decisions

Interprofessional Secondary Transition Practice Requires

A person centered, collaborative, interdependent use of shared expertise directed toward a unified purpose of successful youth/young adult transition outcomes for:

- Post-Secondary Education
- Competitive Integrated Employment
- Community Living and Social Engagement

The Big Picture: Guiding Questions

Ask yourself:

- What is it that we are actually doing to support this student?
- Is it meaningful?
- Will it really help the student to achieve his/her post-secondary goals?
- Does the student's health impact their transition success and to enjoy quality of life?

Considerations for Health and Education Identified in IEP

- Self Advocacy
- Self Care
- Communication
- Assistive Technology and Accommodations
- Disclosure
- Organization
- Intra and Inter Agency Collaboration
  - Education
  - Health
  - Other state and local agencies
    - Financial considerations:
      - insurance
      - benefits
      - Waivers

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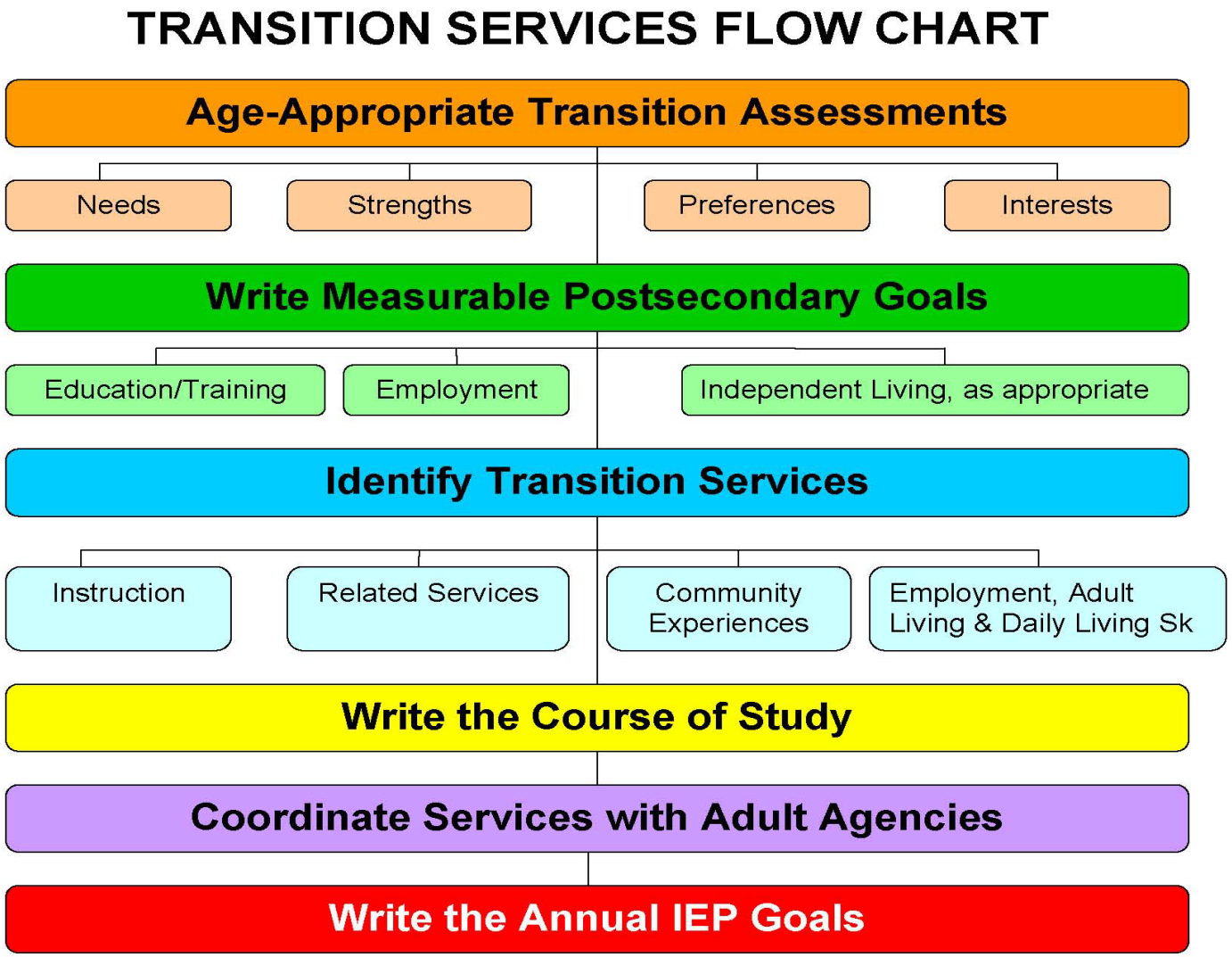
IDEA Secondary Transition Services



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Caroline

- 15-year-old 10th grader
- Interested in becoming a cosmetologist and going to Career Technical Education Program next year
- Recent behavioral concerns in classroom and during transportation
- Positive Behavioral Support Plan developed
- Writing and Math skill deficits
- Medical concern that she has diabetes
- Strengths in art and sports

Age-Appropriate Assessment

- Transition Assessment is a process for gathering relevant information to plan, evaluate or make decisions.
  - Identify interests and preferences
    - Interests: a measure of opinion, attitudes, and preferences
    - Preferences: what the student values and likes
  - Set post-secondary goals
    - Post-secondary education and training
    - Employment
    - Independent Living
  - Further assess abilities, aptitudes and skills
    - Abilities: talents or acquired skills
    - Aptitudes: characteristics that inform us of a student's learning strengths or proficiency in a particular area
- Information should be gathered from multiple people and places over a period of time.

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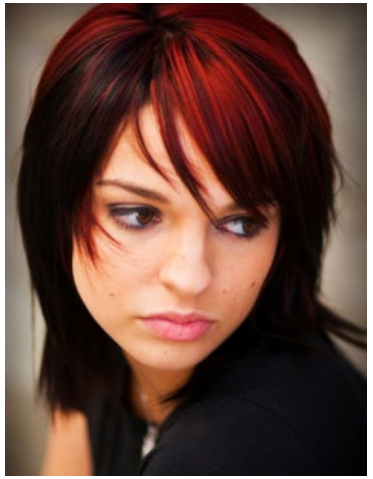
Assessment should not look the same for every student!

Developing Meaningful Goals

- Use ongoing assessment, exploration and experience to align goals with skills, interests and preferences
- Help students learn about requirements needed for their goals
- Further exploration may indicate broader area of interest and help expand career opportunities

Caroline's Post-Secondary Goals

- **Post-secondary Education and Training Goal:**
  - Caroline has a goal of enrolling in post-secondary training in cosmetology or a related field.



- **Employment Goal:**
  - Caroline has a goal of competitive employment in the area of cosmetology or a related field.

- **Independent Living Goal:**
  - Caroline has a goal of living independently at some point after graduation.

Caroline present level for Health

- Caroline has a diagnosis of Type 1 diabetes and is inconsistent in tracking and monitoring her glucose sugar levels and in maintaining a healthy, balanced diet with accurate carbohydrate counts

    - Low sugars cause: irritable, frustrated, non attentive, angry disorganized, difficulty with processing direction, confused, staring/spacey, lack of self initiation with projects and self control.

    - High sugars cause: same as listed above in addition to hyperactivity, impulsive and non responsive.

Caroline's FBA Summary

- The team conducted a Functional Behavioral Assessment in September 2024. Baseline data was collected in the three classes where problems occurred most frequently.... Refusals were defined as "putting her head on the desk, muttering under her breath when asked to complete a task, failing to begin the task and closing her book or notebook with a bang." Some refusals escalate to verbal challenges to staff (saying "make me", swearing, name calling).

- Summary of data indicates that she is refusing about 40% of assignments in general, with the highest rate in English (.6) and the lowest rate in Biology (.25).

- In an interview for her FBA, Caroline indicated that she is frequently embarrassed by her behavior but states that she cannot help herself sometimes. Caroline has several friends at school, but she reported that she is not spending as much time with them outside of school this year. She expressed fear that her behavior will cause friends and peers who have known her since grade school to start to avoid her. In the past two weeks, she has had two absences.

Caroline's Prioritized Needs

Caroline needs to:

- Develop more acceptable alternative (replacement) skills to the behaviors that she displays during assignments perceived as difficult.
- Improve organizational skills that impact assignment completion, as these are needed both at school and in future workplaces.
- Improve skill deficits in writing, beginning with overall fluency and willingness to write.
- Expand her use of standard word processing (i.e. Microsoft Word) features, and graphic organizer software (e.g. Inspiration) and utilize these as a tool for completing assignments
- **Increase ability to track and monitor glucose sugar levels**
- Utilize a program to maintain a balanced diet with accurate carbohydrate counts
- Develop coping skills to employ when anxious, frustrated or angry, as skill deficits in these areas will negatively impact her success in high school as well as future career endeavors. This instruction/support needs to be coordinated with her community service provider.

Sample Transition Section of the IEP → Employment Goal:

Employment Post-Secondary Goal:
Caroline has a goal of competitive employment in the area of cosmetology or a related field once she has completed her training.

Measurable Annual Goal
Yes/No
(Document in Section V)

Courses of Study:
Biology, English, American History, Algebra I, Art

Service/Activity	Location	Frequency	Projected Beginning Date	Anticipated Duration	Person(s)/Agency Responsible
Counseling to develop and use coping strategies to manage anger, frustration, anxiety.	High School	30 minutes/week	10/2/24	10/1/2025	LEA, School Counselor
Development and monitoring of replacement/ coping skills to reduce inappropriate responses to assignments and increase assignment completion.	High School Academic classes and Resource Room	Each school day	10/2/24	10/1/2025	LEA, General and Special Education Staff, Counselor
Instruction on organizational skills and use of a self monitoring checklist to support bringing appropriate materials and assignments.	High School Academic classes and Resource Room	Each school day	10/2/24	10/1/2025	LEA, General and Special Education Staff
Monitoring, tracking and managing blood glucose levels	HS home work and community transportation	As directed by doctor	10/2/24	10/1/25	LEA, Sp ed supervisor, Caroline, Doctor /family, School nurse

Your Feedback is Encouraged

- Watch for an email from Zoom tomorrow and please complete the brief evaluation.
- Contact ntact-collab@uncc.edu if further questions or follow-up from today.

Today's PowerPoint is posted at www.transitionta.org under Training or directly @ https://transitionta.org/trainings/supporting-healthcare-transitions

Final Tips and Takeaways

How You Can Make A Difference

1. Start Early & Empower Youth

- Begin conversations about healthcare transition in middle or early high school.
- Support youth in learning their health history, medications, and how to self-advocate.

2. Use Interprofessional Collaboration

- Engage partners from education, healthcare, and community agencies.
- Aim for shared responsibility and unified goals in transition planning.

3. Include Health in Transition Plans

- Use assessments like Got Transition's Readiness Assessment.
- Incorporate practical health goals in IEPs, especially for students with chronic conditions.

How You Can Make A Difference (continued)

4. Engage School Nurses

- Include them in IEP teams and transition planning.
- School nurses can help students learn critical skills like managing medications and asking health-related questions.

5. Leverage Video Storytelling

- Use family and youth narratives to foster empathy and reflection.
- Videos can support training and inform service planning.

6. Promote Self-Determination

- Encourage student voice and choice.
- Help students set meaningful goals aligned with their interests and needs.

Thank You

Find us:

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