

Healthcare Transition Goals

Youth Voices on Healthcare Transition in the IEP

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UIC's Division of Specialized Care for Children



- DSCC provides free care coordination services for Illinois families of children with special healthcare needs. We operate a few different programs.
- Our mission at DSCC is to partner with Illinois families and communities to help children and youth with special healthcare needs connect to services and resources.
- DSCC is also a Title V partner and is responsible for Illinois' programs for children and youth with special healthcare needs.



DSCC Programs

- **Core Program:** Ages birth to 21 with medically eligible conditions. Those who are financially eligible may also receive financial assistance.
- **Connect Care:** Ages birth to 21 with special healthcare needs who are enrolled in a Medicaid Health*Choice* Illinois plan that has contracted with DSCC for care coordination.
- **Interim Relief Program:** Serves children with eligible mental health or behavioral diagnoses who are in need of an institutional level of care.
- **Home Care Program:** Child or youth in need of in-home shift nursing.



Referring Families



Refer families to our programs
through our website:

<https://dscc.uic.edu/for-providers/refer-a-family/>

DIVISION OF SPECIALIZED CARE FOR CHILDREN

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Transition Tools

These tools will help you prepare for the transition to adulthood.

The transition to adulthood is a significant and exciting time in a person's life. For youth with special healthcare needs and their families, this journey is no less rewarding but requires careful planning and knowledge of valuable resources to assist in the transition. We're here to provide this support and help you and your family prepare for what lies ahead.

We have developed a set of checklists and materials to help youth and their families learn and practice new skills and gain greater confidence and independence. You can search for these resources by category or region on the right side of this page.

We've also compiled some of our most popular checklists and materials into one convenient packet for ease of reference:

- [Transition Toolkit PDF in English](#)
- [Transition Toolkit PDF in Spanish](#)

We also have a booklet that includes information and resources that can be useful in planning for government benefits and health insurance:

- [Guide to Adult Benefits, Services and Resources in English](#)
- [Guide to Adult Benefits, Services and Resources in Spanish](#)

If you are interested in receiving a printed copy of the toolkit or the Guide to Adult Benefits, Services and Resources, please [fill out this short form](#).

We are eager to [partner with you](#) to make the journey to adulthood as successful as possible.

You can learn more about how we help empower youth to have a strong voice in the transition process on our [Youth Voice](#) and [Youth Advisory Council](#) pages.

BROWSE BY CATEGORY

Education

Family Support

General

Medical/Health

Transition

Education

Finance

Guardianship and Alternatives

Healthcare

Independence

Social

Work

BROWSE BY REGION

Champaign

Chicago

Chicago Home Care

Lombard

Marion

Mokena

DSCC YAC Resources

- **DSCC Youth Advisory Council:** <https://dsccl.uic.edu/youth-advisory-council/>

Your IEP, Your Voice

- Learn how to take an active role in your Individualized Education Program (IEP) meetings and speak up about what matters to you.
 - [Your IEP, Your Voice fact sheet in English](#)
 - [Your IEP, Your Voice fact sheet in Spanish](#)



More Resources

Asking for What You Need and How to Get It: A Guide to College Accommodations

- Find out how to request accommodations in college and learn practical tips for advocating for yourself.
 - [Asking for What You Need and How to Get It fact sheet in English](#)
 - [Asking for What You Need and How to Get It fact sheet in Spanish](#)

Your Future, Your Path: Trade School vs. College

- Explore different education and career options after high school and learn how to decide which path may be right for you.
 - [Your Future, Your Path fact sheet in English](#)
 - [Your Future, Your Path fact sheet in Spanish](#)



Learning Objectives

At the end of this session, participants will be able to:

- Explain why healthcare transition is an important part of preparing youth with special healthcare needs and disabilities for adulthood.
- Identify opportunities to incorporate healthcare transition goals and activities into the Transition IEP.
- Apply strategies and resources that help youth build confidence and self-management skills for adult healthcare.

Introduction to Healthcare Transition

What is Healthcare Transition?

- Healthcare transition is the process of getting ready for health care as an adult.
- Healthcare transition is not a single event. It's a process that takes place over many years. It is important to start early.
- It supports youth moving from pediatric to adult healthcare systems.



Youth Perspective: Include Us Early

- Most youth shared that they felt included in healthcare and education decisions, especially when adults intentionally involved them.
- **Takeaway**
 - Start healthcare transition conversations before high school.
 - Give youth opportunities to practice making decisions, even when parents remain involved.



Why does a successful healthcare transition matter?

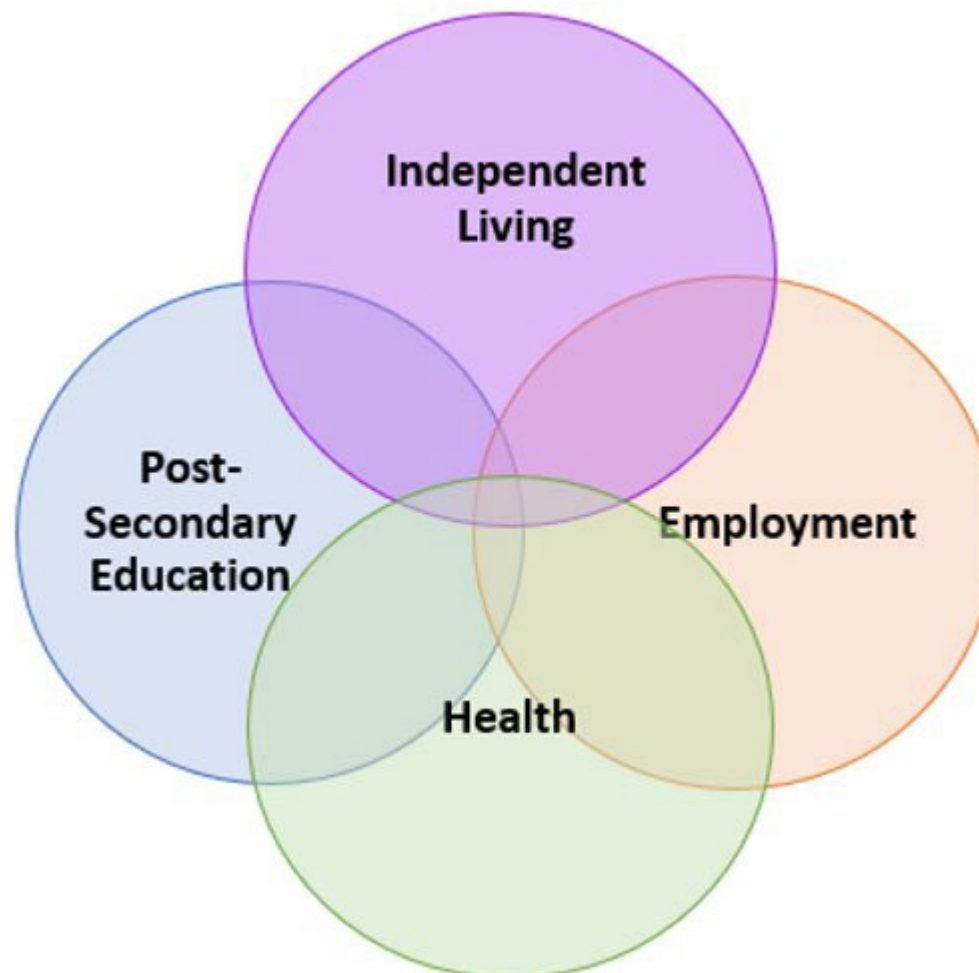


- In 2023-2024, **75%** of youth with special healthcare needs did not receive the services necessary to transition to adult healthcare.



Where Healthcare Transition Matters Most

- Post-secondary education
- Independent living
- Employment
- Overall health



Results of Failed Healthcare Transition

- Low health knowledge
- Higher risk of illness and death
- Trouble following treatment or taking medicine as directed
- More hospital and ER visits
- Higher rates of unemployment and high school dropout



What Youth and Families Say They Need

- Families consistently emphasize the importance of:
 - Clear communication
 - Early and ongoing education
 - Step-by-step preparation for adult care
- Many report that transition planning can feel fragmented or inconsistent across providers.



Managing Healthcare is Complicated

Common Challenges

- Remembering important information
- Managing multiple diagnoses
- Speaking up during appointments
- Finding adult providers
- Explaining their medical history repeatedly
- Invisible disabilities are being misunderstood



Healthcare Transition Goal

- To help youth and young adults gain the skills and confidence they need to take charge of their own health and navigate health services, while still receiving some guidance and support.



What You Can Do

Confidence Grows with Support

- Independence doesn't happen overnight. Youth described healthcare transition as a learning process.
- **What builds confidence?**
 - Family support
 - Educational teams
 - Opportunities to practice
 - Time to learn



Start with a readiness assessment

- This will give you a better idea of the areas your youth or young adult needs more help.
- Based on the results, you can check out tips and tools tailored to your needs.
- Want to see where you're at? Take the assessment yearly to see your progress!



Resources

- [DSCC's Health Care Transition Readiness Assessment for Youth](#)
- [DSCC's Health Care Transition Readiness Assessment for Parents/Caregivers](#)
- [DSCC Transition Toolkit \(Spanish\)](#)
- To request a mailed copy: <https://dsccl.uic.edu/browse-resources/transition-resources/>



Got Transition Resources

- [Health Care Transition Readiness Assessment for use in the Individualized Education Program \(English\) *with funding from DC Health* \(Spanish version\)](#)
- [Sample Goals for the Health Care Transition Readiness Assessment for Students with an Individualized Education Program *with funding from DC Health*](#)



Building Healthcare Skills

Self-Management

- The set of tasks individuals with chronic health conditions perform to keep themselves as healthy as possible.

Examples:

- Taking an active role in your health every day
- Learning about your condition and how to stay healthy
- Working with your care team to manage daily needs



Youth Perspective: Self-management

- What are some ways you've used self-management in your own life?



Examples of Self-Management in Action

- Track symptoms (pain, blood sugar, breathing)
- Use tools like pill boxes or apps
- Follow care plans (medicine, diet, exercise)
- Communicate with healthcare providers
- Recognize when to ask for help
- Advocate for their needs



YAC Youth Perspectives- IEP Goals

- **Self-Advocacy:** Speaking up for themselves and making their own choices
- **Independence:** Learning life, work, and community skills
- **Healthcare:** Learning to manage their own healthcare
- **Organization:** Building skills to stay organized and prepared



Building Skills

- It's important to start building self-management skills early
- IEP goals are a great way to support this growth



Ages 12-14

Help youth learn:

- What [healthcare transition](#) is and [how it works](#)
- About their [own health conditions and allergies](#)
- [About changes to their bodies during puberty](#)
- [To ask their doctor questions and build on self-advocacy skills](#) by participating in medical decisions
- To spend part of the doctor's visit alone with the doctor.
- To take a [healthcare transition readiness assessment](#) to see where they may need more help



Real Word Example

Susan is 12 years old and goes to middle school full-time with the support of her nurse, Tammy. She has a tracheostomy and uses a ventilator at night while she sleeps. Like many kids her age, Susan enjoys spending time with her family and playing video games.

One day in school, Susan's teacher asked the class to explain how they take care of their health. Susan isn't sure what to say and just gives the teacher a blank stare. The teacher shares how important it is to learn about their health needs and gives the class the DSCC tip sheet, Knowing Your Health Care Needs, to help them get started.



Susan's IEP Goal

- I can name my disability and medical diagnosis.



Steps to achieving Susan's IEP goal

- **Teach Susan to explain her condition in everyday words before using medical terminology.**
 - For example, “I have cerebral palsy, which makes it harder for me to control my muscles.”



Achieving Susan's IEP goal

- **Break down the information into small steps**
 1. The name of the disability or diagnosis.
 - You could ask her to describe her condition in 3 words or one sentence.
 2. Describe what it means to have the condition.
 - For example, it affects my ability to breathe and do everyday activities
 3. How it affects their daily life
 - In what ways does Susan need extra help with daily living activities



Susan's Steps Continued

- **Break down the information into small steps**
 4. What supports and accommodations does Susan need
 - Learn about the supports inside and outside of school that can help them succeed. As well as the supports they are currently getting through their IEP.
 5. Create a personal health script
 - For example: I have autism. Sometimes I need extra time to process information, and written instructions help me.



YAC Youth Perspectives

- **Builds confidence:** IEP goals help youth prepare for the future and become more independent.
- **Supports independence:** Goals can help youth take care of their health with less help from family.
- **Provides needed time:** Extra time can help youth learn and manage their health needs.



YAC Youth Perspectives

- **Better coordination:** Support should be easier to understand and connect after leaving school.
- **Family support matters:** Families can help youth speak up for what they need.
- **Not everyone needs changes:** Some youth felt their current support was working well.



Ages 15-18

Help youth learn:

- About family medical history and their own health needs.
- To carry their own [insurance card](#)
- What to do in the case of a [medical emergency](#)
- To practice [making a doctor's appointment](#) and ordering prescription refills
- To spend more time alone with their doctor during visits
- To take a [healthcare transition readiness assessment](#) annually to see where they may need more help



Help youth learn:

- To make their [own appointments](#) and refill medications.
- About their [health insurance and how it works](#)
- To take an active role in doctors ' appointments and [ask when the transition to adult doctors](#) will occur.
- To learn about their [privacy rights now](#) and when they turn 18.
- To work with the doctor to make and share a [medical summary](#).
- Before turning 18, figure out if they will need help making health care decisions.



Real World Examples

Tim is a 16-year-old student at Southeast High School. He attends school full-time and participates in the school's Pre-Employment Career Training (PECT) program. As he prepares to interview for jobs, he is developing important skills that will help him succeed at work.



IEP Healthcare Skills

- One skill Tim needs to improve is **managing his medications**. This means knowing:
 - The names of the medications he takes
 - How much to take (the correct dose)
 - When to take them
 - Why he takes each medication
- As Tim becomes more independent, he will need to take his medications on his own at work.



Tim's IEP Goal

- I know how to read and follow the direction labels on my medicines, I know the amounts of medicines I take, and I know when to take my medicines.



Tim's Steps to Success

- Tim will need to break down his goals into smaller, manageable steps to be successful.



Tim's Steps to Taking His Medication as Prescribed



1. Learn to Identify His Medications
2. Read Medication Labels
3. Understand the correct dose
4. Know when to take medications
5. Follow medication directions
6. Demonstrate independence



Insurance and Program Changes

Types of Health Insurance

- Public or Government Insurance
 - Medicaid
 - Medicaid Managed Care Plans
 - Medicare
- Private Insurance Plans
- TRICARE
- Campus Health Plan (for college students)
- Other limited benefit plans: Prescription, Dental and Vision



Staying on a Parent's Insurance Plan

- A young adult can stay on their parents' private insurance plan through age 26. Age 30 for military insurance.
- It is possible for a disabled adult child to remain on their parent's private insurance plan after they turn 26.
- Different insurances and employers have different criteria to stay on after age 26. You must talk to your insurance plan or employer.



Medicaid Transition at Age 19

- All Kids coverage ends at the end of the month you turn 19
- Apply for Adult Medicaid 1–2 months before your 19th birthday
- Medicaid will review your application and decide if you qualify



Medicaid Transition at Age 19

- You must apply for your own case as the “head of household”
- After age 19, approval is needed if you have more than 4 prescriptions
 - Learn More: [Four Prescription Policy](#)
- At age 21, some coverage changes for benefits like dental care



Adult Medicaid Programs

- ACA Adult Medicaid
- Aid to the Aged, Blind and Disabled
- DCFS
- Health Benefits for Workers with Disabilities (HBWD)
- Family Care
- Moms and Babies

[Illinois Medicaid Programs and Eligibility Guide \(Spanish\)](#)



Medicare

- Medicare is not a program you apply for; it is a program you become eligible for.
- You must receive Social Security Disability Insurance (SSDI – this is not the same as SSI) for 24 months as a disabled young adult before becoming eligible.

[Medicare Fact Sheet \(Spanish\)](#)



Resource

DSCC's Guide to Adult Benefits Services and Resources (Spanish)

- This booklet includes information and resources to help plan for government benefits and health insurance.
- <https://dsccl.uic.edu/browse-resources/transition-resources/>

Guide to Adult Benefits, Services and Resources

Remember...



Transition is a process.



Having a plan is crucial.



Be flexible, changes will happen.



Programs and services vary in eligibility and funding. They also will change over time. Be sure to contact the agency for current information.

This booklet includes information and resources to help plan for government benefits and health insurance.

Final Thoughts

Final Thoughts from Our YAC Members

- **Encourage youth to advocate for themselves.**
- **Remind youth that it's okay to ask for help.**
- **Be patient and remember:** This may be your first time supporting them, but it's not their first experience managing their health.
- **Pay attention to the small things.** Important details can easily be overlooked or forgotten.



Takeaways

- Healthcare transition is a lifelong process.
- IEPs can be a powerful tool.
- Self-management skills are essential for adulthood.
- Start early and build skills over time.
- Youth voices matter.





Thank You

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