



Healthy and Ready for College!

by Debbie Gilmer, Kathleen Blomquist, Theresa Glore, and Toni Wall

INTRODUCTION

When students with intellectual disabilities are getting ready to go to college, who will provide healthcare is just one of many issues that families and students may discuss. But when the student has special healthcare needs, the planning needs to be more purposeful. Participating in postsecondary education presents a number of challenges to youth with special healthcare needs. This brief focuses on healthcare transitions and provides strategies that can be used in college and afterward to help young people stay healthy and ready for the future.

When they are in college, youth will need to take greater responsibility for managing and making decisions about their healthcare. To prepare for this, young people and their families should start developing health knowledge and skills early in adolescence. This brief will help support discussion between families and youth around the following questions:

- What do I need to know and do to manage my health at when I am in college?
- How will I take responsibility for my medications, therapies, or routines, or my special diet?
- Where will I get healthcare services when I am at college?
- How will I communicate my needs to various healthcare providers? (Communication, questions, self-responsibility, health records, etc.)
- How will I pay for my healthcare?

The Role of Parents

Preparing for successful transition takes practice. Parents, along with educators and other community support

providers, can help youth prepare for and accept the responsibilities that go along with adult healthcare. Teaching youth to anticipate and prepare for their health needs, introducing youth to the adult healthcare system, and providing youth with opportunities to practice health management and communication skills should be critical components of any transition plan.

Parents can successfully assist their sons and daughters to assume greater responsibility for their healthcare in the following ways:

- Encourage youth to talk with healthcare professionals.
- Let youth spend time alone with their healthcare providers.
- Encourage increasing responsibility for health matters, including making appointments, refilling prescriptions, and consenting to care.
- Help youth understand their health condition(s).
- Help youth maintain their health records.
- Help youth plan for the transition from pediatricians to adult healthcare providers.
- Explore health insurance options as youth approach adulthood.

Youth who are prepared to successfully transition to adult healthcare accept responsibility for their health and wellness; know their bodies, catch health problems early, and work with their doctors and other healthcare providers to maximize their health; follow guidelines for health screenings and immunizations; exercise, watch their diets, and get needed rest; and avoid alcohol, tobacco, and other drugs.

HEALTH TRANSITION SKILLS CHECKLIST

Parents can use this checklist to frame the conversation about all the things that go along with managing your own healthcare at college. It can identify some skills that can be worked on during transition, and also identify those things that the student may need support with while they are at college. The goal is to be independent in as many of these lifelong skills as possible, with an acknowledgement that for some students, there will be a need for support in some areas. This will be helpful information to have when the student and family are doing campus visits, so that there can be a good match between the supports the college program offers and the needs for support of the student.

(adapted from JAX-HATS and HRTW – see resource list)

Skills for Health	I can do this	I need to learn to do this	I need help with this	Does not apply
Understand my healthcare needs and disability, and explain my condition and needs to others as needed.				
Explain to others how my family's customs and beliefs might affect healthcare decisions and medical treatments.				
Know the names of my doctors and other healthcare professionals and how to contact them.				
Know the symptoms of my health condition that need quick medical attention.				
Know what to do if I have a medical emergency.				
Know what allergies I have.				
Make my own medical appointments.				
Request my own prescription refills.				
Before a medical appointment, prepare written questions to ask.				
Sometimes see my doctor by myself.				
Answer many or most of the doctor's questions during a healthcare visit.				
Carry my important health information with me every day (e.g., medical summary, including medical diagnosis, list of medications, allergy information, doctor's numbers, pharmacy number, health insurance card).				
Co-sign the "permission for medical treatment" form (with or without signature stamp, or direct others to do so).				
Help monitor my medical equipment so it's in good working condition (daily and routine maintenance).				
Pay my co-pays for medical appointments.				
Have a plan so I will have health insurance after I turn 18.				
Know where the health center is on my college campus.				
Know who to ask if I have questions about my healthcare.				

Finding a New Doctor

As youth transition into adulthood, they will move from pediatrics into adult medicine (i.e., family doctors or internists). If they are moving to a different town to go to college, they may also need to find a new doctor. It is very important for them to find a doctor who will meet their healthcare needs, with whom they can work well, and whom their health insurance plan will cover.

A number of questions need to be answered regarding the selection of a new doctor. For example, is it important to find a doctor who will take time with the youth during an office visit to explain things and listen to them? Is it more important to be seen by someone who is “good” in his/her field but who might not have the best bedside manner? Is it important that the new doctor be knowledgeable about the youth’s specific healthcare needs? Is the new doctor willing to let the youth provide that information, or to connect the new doctor with those who could provide medical insight?

Before youth start looking for a new doctor, they should answer these questions:

- How will I get to my provider’s office?
- Do I need an office that is wheelchair accessible, or do I need other special assistance in the doctor’s office?
- Are the office’s business hours convenient?
- How do I contact the doctor at other times?
- If I need hospitalization, where do I go?

Ways to find a new doctor include asking their current doctor for recommendations, checking out the doctor their parents or other family members see, checking around by calling a family support group or adult disability agency, asking adults with health needs similar to theirs for recommendations, referring to their health insurance company booklet of approved providers, asking a Vocational Rehabilitation or Independent Living Center counselor, and finding out whether their college/university student health center will take their health insurance and can provide them with services if they are not a full-time student.

HEALTHCARE ON THE COLLEGE CAMPUS

Many college campuses offer a range of healthcare services from walk-in clinics to comprehensive healthcare services including mental health services and counseling. The range of services varies, but some level of health services can be found on almost all college campuses. It is important to find out if a student who may not be fully matriculated but is attending a college program for students with intellectual disabilities is eligible to receive services from the campus health services. These services, geared toward young people who are all learning to be more responsible for their own healthcare, can be a supportive environment to practice the skills for health mentioned earlier.

Privacy of Health Information

In most states, before a youth’s 18th birthday, medical treatment requires parental consent except in very specific circumstances, because parents have legal responsibility for the youth’s healthcare. The youth’s verbal or written assent for treatment is recommended but not required.

On a youth’s 18th birthday, legal responsibility for consent shifts to the youth. Under the Health Insurance Portability and Accountability Act (HIPAA), healthcare professionals cannot discuss health information with the youth’s parent or guardian unless the youth specifically grants permission. Strict adherence to HIPAA rules might mean that the youth’s parents and guardians suddenly cannot get information about the youth’s health and healthcare that they had always thought was their right and responsibility. Managing this transition in decision-making and information-sharing requires careful planning. The youth may elect to sign a HIPAA waiver to give their parents access to medical information; however, this is not legally required. It will be important to youth and their parents to discuss this situation so youth can get help if they need it and parents can assist the youth if desired.

Health Insurance

Having health insurance is important for young people with disabilities because it affects their ability to get medical care, stay well, and prevent further health problems. Health insurance is typically obtained from an employer (theirs or

their parents'), directly from an insurance company, or through a government-sponsored health plan such as Medicaid, Medicare, Children's Health Insurance Program (CHIP; covers youth up to age 19), TRICARE (for military families), and state programs for children with special healthcare needs (Title V CYSHCN programs cover youth up to age 21 in most states).

The following questions should be addressed during the transition period so that the youth will maintain health insurance coverage:

- **Can I stay on my family's plan?** New healthcare reform allows students to stay on their family's insurance plan until age 26, but students should be sure to check on their specific plan to make sure.
- **Can I get insurance through my college or university?**
- **If I am receiving Medicaid as a child, will it continue after I turn 18?**
- **If I am not on SSI, will I be eligible at age 18, so I can get Medicaid?**

CONCLUSION

Thanks to the outstanding advocacy of youth, their families, educators, and policymakers, youth with intellectual disabilities now have access to postsecondary education, careers, and valued and meaningful lives in integrated communities across our nation. Ensuring that the transition process addresses health and healthcare issues will better support youth with intellectual disabilities to be healthy and ready to succeed in college.

RESOURCES

Think College: Healthy & Ready for College

www.syntiro.org/think-college-healthy-and-ready-for-college

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Kathy Blomquist, PhD, served as a co-director and consultant to the Healthy & Ready to Work National Resource Center and was involved in HRTW efforts since its inception in 1994. Retired now, Dr. Blomquist spent many years working for the Kentucky Commission on Children with Special Health Care Needs. Previous work included public health nursing in Ohio, school nursing in Texas, and teaching nursing in Illinois and Kentucky. She participated in several research and evaluation projects at the University of Kentucky. Dr. Blomquist authored "Health, Education, Work, and Independence of Young Adults With Disabilities," which was awarded the Nan Hilt Research Writers Award by the Editorial Board of Orthopaedic Nursing for the most significant contribution to the orthopaedic literature in 2006.

Theresa Glore, M.S. is a consultant to the Kentucky Cabinet for Health and Family Services where she developed the state plan for electronic health information exchange and is now working on state implementation of the Affordable Care Act. She served as a liaison to state Title V CYSHCN programs for the Healthy & Ready to Work National Resource Center and assisted in the development of tools and materials. Ms. Glore formerly served as a deputy with the Kentucky Commission for Children with Special Health Care Needs. Prior to the Commission, she worked in various capacities in the Kentucky Department for Public Health, directing health education and community health status assessment, HIV prevention and services, and the Behavioral Risk Factor Surveillance System.

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