What does Health Have to Do with Transition? Everything!

By Ceci Shapland

Introduction

Adolescence is a time for dreaming—for youth to imagine and set a course for the future. High school students naturally spend time imagining the future—if and where to continue their education, to find a job or pursue a career, to move away from home, or to start a family. The Individuals with Disabilities Education Act (IDEA) includes a process to help youth with disabilities turn their dreams into reality. This Parent Brief provides information on the benefits of and strategies for including health in the Individualized Education Program (IEP) process.

For each student with a disability beginning at age 14 (or younger, if determined appropriate by the IEP team), IDEA requires that the IEP include a statement of transition service needs [§300.347(b)]. Transition services are a coordinated set of activities that promotes movement from school to post-school activities, including postsecondary education, vocational training, employment, continuing and adult education, adult services, independent living, or community participation [§300.29].

Health needs to consider as part of transition planning:

- good nutrition practices;
- proper hygiene practices;
- the effects of alcohol, tobacco, and other substances;
- the importance of exercise; and
- reproductive education.

It is not common practice to identify health-related needs and goals when developing a statement of transition services within a student’s IEP. However, lack of attention to health needs and health management can jeopardize goals for learning, working, and living safely in the community. For this reason it is important that young people with disabilities and special health needs know how to manage their own health care and work with appropriate professionals as partners in their care.

Health is an important factor to include even if chronic health concerns do not exist. All people must deal with health problems and learn how to maintain good health.

Transferring responsibility for self-care to an adolescent is a complex process. It requires assessing a variety of factors, including the complexity of a youth’s health needs, his or her physical and cognitive abilities and degree of self-determination, as well as family factors (Kelly, Kratz, Bielski, & Rinehart, 2002). Cultural factors such as values, health care practices, and beliefs about disability must also be considered (Geenen, Powers, & Lopez-Vasquez, 2001).
Addressing Health Concerns During the Transition Process

The IEP lends itself well to evaluating factors needed for successful health outcomes as youth transition from special education to the adult world. Their needs can easily be incorporated into the IEP as annual goals and objectives, or benchmarks.

Addressing Family Health-Care Concerns

Family involvement generally contributes to better school and medical outcomes. Because it is not yet common practice, families may find they have to bring health-care concerns to the attention of the IEP team in order for their son or daughter’s health needs to be addressed. It can also be very difficult for parents to give full responsibility for health issues to a young adult because of the obvious dangers of mismanagement.

Starting at an early age, planning ahead and identifying safety nets and emergency plans are important. Physicians can help youth and families solve problems in these areas.

It is beneficial to clearly identify concerns and discuss best- and worst-case scenarios. Support and emergency plans can be developed, and youth can become aware of the impact of certain behaviors on their health in order to make informed choices. This approach has been successful in alleviating some fears and providing teens with a better understanding of how to maintain their health. These and other health-care issues can be addressed in the statement of transition services in a student’s IEP.

Following Joe

At age 19, Joe is a dynamic young man who aspires to be a chef as well as to have his own apartment. Joe has mild mental retardation and a severe seizure disorder. His health depends on how well he remembers to take his medications and follow his doctor’s advice about getting enough rest and avoiding alcohol. Joe currently lives at home, and his mother reminds him to take his medications and follow the doctor’s recommendations.

Joe is meeting the transition goals in his IEP related to employment, postsecondary education, and community living. In the past year, Joe has attended a community college to study food preparation, and hopes to graduate as a sous-chef.

Joe’s mother is concerned about how he will manage his health.

- Will he remember to take his medication every day?
- Who will help Joe make the check-up and follow-up appointments that have helped keep his seizures under control?
- Who will remind him to rest and avoid alcohol or other substances that would interact with the seizure medication and threaten Joe’s health?
- Currently, Joe sees his childhood doctor, a pediatric neurologist. Will he need to change doctors, and if so, who will be his physician?

(an assistant to a head chef) at the end of the semester. Joe’s mother has found him an apartment in the city with community support nearby.

As graduation approaches, however, Joe’s mother is concerned about how he will manage his health and seizure disorder when he moves from the family home to his own apartment.

Joe’s mother has some important concerns that can be addressed as part of Joe’s transition planning process. His health needs greatly affect how he functions day-to-day and will influence...
his ability to keep a job and live on his own with limited support. Despite the excellent planning for job training, employment, and a new home, all Joe’s plans could be in jeopardy if his health needs are not addressed as part of the transition planning process.

**Transition and the Medical Community**

During the past 20 years, awareness of health as an important part of transition planning has been growing within the health-care community. In 1993, the Maternal and Child Health Bureau (MCHB) established the Healthy and Ready to Work Initiative. Today, projects around the nation are working with state health departments, hospitals, school systems, families, and youth to ensure that health is part of the transition process and to provide system of change models.

In 2002, MCHB funded a Healthy and Ready to Work National Center to provide information and resources for families, youth, health and education agencies and professionals, and others involved with youth who have special health needs.

A recent American Academy of Pediatrics position paper (2002) provides guidance to health-care providers on how to help youth with disabilities move from a child-focused to an adult-focused health-care system. The Academy agrees with others that “health-care transition facilitates transition in other areas of life as well, such as work, community, and school.”

**Making It Work: Health and the IEP Process**

Although inclusion of health related needs as part of transition planning is growing within the health-care community, putting this principle into practice continues to be a challenge—particularly because physicians are generally not participants in the IEP. The key question remains: How can schools consistently and creatively include health issues in transition planning?

School nurses generally assess the health status of students with disabilities and present information to the IEP team in a written statement. This is an important step in the IEP process. However, this assessment does not address health as a life area that may need to be considered to promote independence and transition to adulthood.

Youth and families need to learn strategies to effectively manage health issues. For example, youth may benefit from having a filing system to keep medical records organized, to know when to make follow-up appointments, and to find historical information about diagnoses and treatments.
Health and Key Areas of Transition

Viewing health as an element of transition planning may include assessing a student’s needs in several key areas of transition. For example, consideration may be given to how health might affect employment choices, post-secondary education, and independent living. The IEP team may develop health maintenance plans and examine transition choices that are consistent with the student’s health needs. The following are health questions related to several critical transition decisions. The questions address the needs of Joe, the young man in the example introduced earlier in this brief.

Jobs and Job Training:

- Does Joe need to take his medication at work? If so, what arrangements need to be made to accommodate this?
- Will Joe’s medication affect him on the job? Will it make him drowsy? If so, should the timing of his dosage be readjusted to his work schedule? Does this mean that changing his work hours may endanger his health?
- Should he disclose his seizure disorder to his supervisor and co-workers?
- Are there job duties that he cannot do, such as operating some machinery, because of certain medications?
- Does he know the side effects of his medication and important changes in his condition that he should report to his doctor?
- Does he understand the healthy lifestyle he needs to lead so his seizures will be in better control?
- Does he know the importance of healthy meals, exercise, rest, and good hygiene?
- Does he have an emergency plan in case he needs help at home, work, or school?

Postsecondary Education

- Does Joe need to take his medication while in school?
- How will it affect his performance?
- Should he disclose information about his health to the teacher?
- Will Joe need accommodations in his schedule or course load to maintain his health and be successful in school?
- Does Joe have an adult medical practitioner who will attend to his adult health needs?
- Does he know how to go to the doctor and how to use public transportation to get there?
- Does he know when, how, and where to fill a prescription?
- Will he continue on his family’s health insurance plan or have insurance through work or a public program?

Leisure and Recreation

- Does Joe understand the effects of recreational drugs, alcohol, or tobacco on his health and seizure disorder?
- Should he tell his friends about his seizure disorder?
- Will his medication affect his choice of activities?
- Does Joe understand his seizure disorder?
- Does he carry his own insurance card and emergency medical information?
- Does he have a system for remembering to take his medication on his own?
Health Transition Goals and Objectives

The following are possible health transition goals and objectives that Joe and his family might consider.

**Goal:** I (Joe) will learn about my seizure disorder and my health needs to ensure my good health, so I can live more safely in the community.

**Objective 1:** I will learn five facts about my seizure disorder and make a 10-minute presentation in health class.

**Objective 2:** I will learn two or three side effects of my medication and learn when to report any changes in side effects or new symptoms to my doctor.

**Objective 3:** I will develop an emergency plan for when I am living on my own.

**Objective 4:** I will identify and interview two or three physicians to choose a new doctor who will help me manage my adult health care.

These are a few possible goals and objectives for Joe as he continues through his transition. Others can be added as Joe accomplishes these objectives and learns more about managing his own health care. Youth need to receive information that is understandable and appropriate to their individual needs in order to make good decisions. The transition process helps a young person begin to manage his or her own health by 1) providing a structure for gathering information from physicians, and 2) accessing the expertise of the IEP team to ensure the information is easily learned and understood and to assist in making any modifications or accommodations. Including health goals and objectives like those above in the IEP transition planning process allows an adolescent to learn skills needed to make health decisions, identify resources in the community, and achieve successful postschool outcomes in all areas of transition.

*Author Ceci Shapland is a Co-Director of the Healthy & Ready to Work National Center.*

**References:**


**Resources:**

- Healthy & Ready to Work National Center • www.hrtw.org
- PACER Center • www.pacer.org
- National Center on Secondary Education and Transition (NCSET) • www.ncset.org

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1. Keep in mind that unless transition services are considered special education, i.e., provided as specially designed instruction or related services required to assist a student with a disability to benefit from special education (Sec 34 FR 300.29 (6)); IDEA only requires that an IEP include a statement of transition services needs, not goals and objectives.
IDEAs that Work

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Access Parent Briefs and other NCSET materials online at: www.ncset.org.

National Center on Secondary Education and Transition


NCSET works to increase the capacity of national, state, and local agencies and organizations to improve secondary education and transition results for youth with disabilities and their families. The Center is headquartered at the University of Minnesota and is a partnership of six organizations, including PACER Center. NCSET:

- Coordinates national resources that connect policymakers, administrators, professionals, educators, employers, parents, and youth with disabilities to information and useful resources;
- Hosts capacity-building institutes and workshops, national summits, national teleconference calls, and additional training opportunities;
- Develops research-to-practice tools for everyday use; and
- Provides technical assistance and outreach.

PACER works with NCSET to represent family perspectives and disseminate information to a national network of federally funded parent centers and the families they serve.
Changing doctors is never easy. When you’re a teenager new to advocating for your own health care, or one who has a chronic illness like diabetes or cystic fibrosis, it can be even more challenging to make the transition.

A new clinical report provides detailed guidance to pediatricians, family physicians, and internists to support all adolescents, including those with special health care needs, as they transition to an adult model of health care. The clinical report, "Supporting the Health Care Transition From Adolescence to Adulthood in the Medical Home," from the American Academy of Pediatrics (AAP), American Academy of Family Physicians (AAFP) and American College of Physicians (ACP), is published in the July 2011 issue of *Pediatrics* (published online June 27).

"Pediatricians have asked how to incorporate better transition supports into their busy practices, and the new clinical report with its detailed practice-level guidance will help show them the way," said Carl Cooley, MD, FAAP, co-chair of the group who authored the report. "All youth and young adults deserve seamless access to a primary care medical home and any necessary specialty care through all of life’s transitions."

"Finding adult primary and specialty care providers for youth with chronic conditions has been a challenge for pediatricians, youth and families," said Paul J. Sagerman, MD, FAAP, co-chair of the authoring group. "As ‘best practice’ for both pediatric and adult clinicians, the new clinical report will improve access to adult health care."

Ideally, children should transition to adult-oriented health care between the ages of 18 and 21 years. For adolescents seeing a pediatrician, the transition will involve choosing a new physician, transferring medical records, and communicating treatment histories and insurance information. Although adolescents seeing a family physician may stay in the same practice, they may still need to transfer specialty care to adult subspecialists.

"All adolescents face unique health issues and have complex needs when it comes to care, but this is particularly true for teens dealing with chronic disease or disability," said Roland Goertz, MD, MBA, FAAFP, president of the AAFP. "Having a medical home can provide stability during this time of change, and this report provides excellent guidance for family physicians and their care teams to help young people and their families follow a healthy path to adulthood."

The transition requires help from the doctors on both sides, including preparing the adolescent to take charge of his or her own health care. Most young people with chronic illnesses will survive into adulthood and will need to find physicians who are trained in treating those conditions.

"Internal medicine specialists and subspecialists are often not prepared for the medical and social support needs of young adults with chronic or rare health conditions," said Michael S. Barr, MD, MBA, FACP, ACP's
Tips for Youth and Young Adults

So, how do you find a doctor who will meet your youth's medical needs, whose services will be covered by your health plan, and who can provide the care you are looking for?

Before you start looking for a new doctor, think about what you want:

• Is the office location important?
• Will you need help with transportation?
• Do you need an office that is wheelchair accessible or do you need other special assistance in the doctor's office?
• Are office hours convenient?
• How do you contact the doctor at other times?
• What hospital do you want to use, and is this doctor on the staff there?
• Which is most important to you: someone who will take time with you during an office visit, or someone who is an expert in his or her field but whose time with each patient is more limited?
• How important is it that your new doctor is knowledgeable about your condition?
• Do you think you can provide the doctor with information about your condition or connect the new doctor with those who could provide specific medical insight?

Strategies to consider in your search for a new doctor:

• Ask your current doctor for possible references.
• Check out the doctor your parents or other family members see.
• Call a family support group or adult disability agency for options.
• Ask for recommendations from adults who have health needs similar to yours.
• Refer to your health insurance company booklet of approved providers.
• Ask a Vocational Rehabilitation or Independent Living Center counselor.
• Find a university health center (sometimes there are research studies going on which offer free care).
• Contact your local Medical Society, American Academy of Family Practitioners, or Internal Medicine Society either through the Yellow Pages or on their national websites for referrals.
• To find agencies or other community services mentioned above, see Community & Professional Services.

Since your wellness depends on the medical services you receive, it is important that you are comfortable talking with your new doctor and feel that he or she understands your concerns. Consider scheduling a "get-acquainted" interview before you make a final choice of a new doctor. You will have to pay for this visit, as it is NOT normally covered by insurance benefits. An ideal interview time is about 15 to 30 minutes and should not waste your time or the doctor's. To learn how to communicate with health care professionals, see Communicating with Doctors and Other Health Care Providers (126 KB).

The best time to see a new physician is when your health condition is stable so you aren't asking for crisis care while getting acquainted with a prospective health care provider.
Think about (and write down) questions that are important to you:

- Is the doctor knowledgeable about your health issues and/or willing to learn from you and from previous doctors?
- Do you like the communication style with the doctor and in the office?
- Are you satisfied with office practices and access during an emergency or in urgent situations?
- Do you have access to hospitals and specialists if you need them?
Moving Into Adult Health Care

What Do Parents Need to Know?

A guide for parents of young adults with and without disabilities


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Connecticut Kids As Self Advocates
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Connecticut Kids As Self Advocates

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Principal Authors
Michael Adamczyk
Emily Ball
Kellie Barkyoubm
John Curtin
Maria D’Addario

Principal Authors
Andrew Farrington
Faye Frez-Albrecht
Sarah Liebeskind
Shannon Mazurick
Millie Rivera

Editors
Jessica Dybdahl, Editor
Sarah Honigfeld, Editor
Molly Cole, Adult Ally
Heather Northrop, Adult Ally

For more information and to obtain this book, please contact the following:

Connecticut Department of Public Health
Family Health Section
CYSHCN Program
410 Capitol Avenue, MS#11MAT, P.O. Box 340308
Hartford, CT 06134
860-509-8074

CT-KASA
Connecticut Kids As Self Advocates
www.ctkasa.org
Introduction
So Your Child has Become an Adult! Now What?

Turning 18 is a magical moment for most young adults. According to the law, all you have to do to be an adult is become 18 years old. Just like that, you are legally an adult!

That may sound simple, but as any adult knows, turning 18 doesn't mean you just know everything you need to know about being an adult. For parents, the journey to transform their child into an adult is a long one, and requires planning, fortitude and patience. Teaching your young adult to be responsible for their health care is a journey that begins in childhood. This booklet is about the steps parents can take to help their child to lead a healthy, independent adult life. For some parents, whose children have required a lot of assistance and support to meet the challenges of their disability, this vision of independence is not easily attained. This booklet was written for you by young adults with disabilities who have been on this journey with their parents, and who have many ideas about how to make this a smooth and successful process regardless of your child's disability.

This booklet will help you think about the things you need to do to assist your young adult to take care of their own health. It will help you to work with them to think about their own health care needs, organize their information, talk to doctors and other health care providers, and manage their own medications.

This booklet is about preparing your young adult to be healthy and ready for life!
START EARLY!!

It is up to a parent to ensure that a child knows and understands his or her disability. Talk about it; let them meet other children with similar needs. Give them the words to explain their disability to other children they meet. Talk to them lovingly and with hope.

Your child may have questions about why they are different. They can really benefit from straight talk. It is important to give your child's disability the proper name, and explain what that means. This can head off anxieties and better prepare your child to seek appropriate health and support services later in life.

One strategy is to tell the child that everyone is different: some kids wear glasses, some have allergies and can't eat certain things, or sneeze a lot, and some have weak muscles, cannot see, or cannot hear. Everyone learns differently, and some children need special help to learn.
What is a Medical Home?

A medical home is not a place, but a way of delivering health care that is coordinated, patient and family centered and culturally appropriate. The medical home is also known as an approach to providing primary care that builds partnerships between individual patients, and their health care providers, and when appropriate, the patient's family. When health care is delivered through a medical home, your young adult will have better access to health care, increased satisfaction with care, and improved health.

A key part of the medical home is care coordination. This includes assessing your needs, planning the right services and supports, delivering those services and supports, and measuring how well these services and supports meet the child and family's individual needs. Building a sense of trust between families and the medical home and responding to their needs in a timely and coordinated manner is essential. Care coordination within a practice will:

- Make it easier to access services
- Ensure consistent and coordinated care
- Provide needed support to individuals and families
- Improve health, developmental, educational, vocational, psychosocial and functional outcomes
- Maximize efficient and effective use of resources
At the Doctor's Office

As soon as your child can understand, you should explain to them why they are going to the doctor and what will happen. When appropriate, help them to think of questions they may want to ask when they go to the doctor. If your child needs help organizing their questions, think of other ways to have them ask questions, including working with them to write down their questions and e-mail them to the doctor ahead of time. Encourage the doctor and other health care staff to talk directly with your child when he or she asks a question. You can help explain the answer to your child.

Many young adults don't have the same chance to see the doctor alone, even for part of a visit, and they don't learn how to manage their own health care or talk to the doctor alone. Yet, many young adults who do not have disabilities begin to see their doctor alone for a least part of a visit by the time they are 11 or 12 years of age.

As the parent, one strategy is that you may go into the exam room for some part of the appointment, but not all of it. You will need to prepare both your young adult and the doctor for their time together—communication strategies, etc.
Help Your Young Adult Learn What To Do
If They Don’t Agree With Their Doctor

Sometimes your pediatrician or primary care doctor and other health care providers do not agree about your young adult's diagnosis or treatment. This can be a very difficult situation for you and your young adult as you try and make good choices about medical treatment. You have several options:

- **Seek a second opinion.** Ask to see another doctor who may specialize in the treatment of your young adult's symptoms or diagnosis, or another primary care doctor. Explain that you are unsure how to decide about your young adult's health care choices, and need another opinion. Many insurance plans cover second opinions.

- **Seek help from a care coordinator in your medical home.** If your young adult is receiving care in a medical home, you and your young adult should sit with your care coordinator and review the information that all the providers have given. Together, you can decide what to do next, including having a meeting or phone call with the providers to discuss your choices, or getting help in finding a provider for a second opinion. It is important to let people know how difficult it is when your family gets different information and treatment plans from different providers.

*The most important thing to remember is that your young adult has to make an informed decision about their care. Encourage them to tell their doctor if they are confused or do not agree. Then they have to make a choice about what to do next. This means getting as much information as they can before they choose the right treatment plan for them.*

6
Let Your Young Adult Take Charge

By the time your young adult is 16 or 17, help them call the doctor to make their own appointments. If your young adult has difficulty speaking on the phone, help them find an alternate way to schedule appointments. It is important that they know the date, time and location of all medical appointments, and the reason for each appointment. You can use a calendar with them to write down appointments. You can also mark on a calendar when they need to order or refill medications and other information.

**Encourage your young adult to keep their doctor’s number and insurance information with them at all times.** This is information they will need to know as an adult. They need to be aware of how bills are paid, what they have as a co-pay, and how all payments are made. Help them understand the type of coverage they have, and the limits to their coverage.

Encourage your young adult to be prepared for emergencies! Assist them in completing an emergency information form, with your names, and the names of others to contact in case of emergency. Don't forget to teach them ICE (In Case of Emergency). ICE is the contact that all emergency responders will look for in a cell phone. If your young adult carries a cell phone, help them program in the emergency contact number under ICE.
Partnering With Your Young Adult's Primary Care Physician

Discuss your plan to help your young adult take charge of their health care, and ask
the doctor and office staff to assist you. This can begin with letting your young adult
register at the desk when he or she arrives, presenting the insurance cards, going into
the exam room alone, scheduling appointments with the staff and making the co-pays.
It includes encouraging your young adult to ask their own questions, and encouraging
staff to talk directly with your young adult.
Finding A Doctor to Treat Your Young Adult With A Disability

As your young adult approaches age 18, ask their doctor for input on the age to transfer care to an adult health care provider. You may need help in finding another doctor who understands the unique health needs of your young adult. Talk with your young adult’s doctor and care coordinator about choices. Some families choose to have their young adult receive medical care from the physicians who treat the parents. This may work well for some families. Some families ask for referrals from their pediatrician. Others dialogue with other adults with disabilities to learn where they receive their care.

There are many things for you and your young adult to consider—accessibility of the office, knowledge of the disability, other young adults with disabilities treated by this physician, and whether or not they will accept your young adult’s insurance.

In most cases, there will need to be an initial discussion of special health care needs in addition to the transfer of records that will routinely occur.
What IS My Role in Managing My Young Adult's Health Care?

You may always need to be available to answer questions and assist your young adult according to their abilities. But it is critical that your young adult develop the skills, confidence and strategies to navigate the adult health care system in advance of turning 18. And after that, there is no magic date when your young adult won't need to ask you questions.

The difference is-it is now their responsibility to know when they need help and seek your assistance. If you do your job when they are young, this can be a smooth and easy process that allows your young adult the independence to manage their own health care!!
Quick Links to Health Care Transition Resources

Connecticut Department of Public Health
Youth with Special Health Care Needs
  • http://www.ct.gov/dph/cwp/view.asp?a=3138&q=432684

Connecticut Kids As Self Advocates (CT KASA)
  • http://www.ctkasa.org

Got Transition? National Health Care Transition Center
  • http://www.gottransition.org/

Health Care Transitions: The Institute for Child Health Policy at the University of Florida
  • http://hctransitions.ichp.ufl.edu/hct-promo/

Healthy and Ready to Work National Resource Center
  • http://www.syntiro.org/hrtw/

National Center for Medical Home Implementation - Transitions
  • http://www.medicalhomeinfo.org/how/care_delivery/transitions.aspx

United Way of Connecticut 2-1-1 Infoline
  • http://infoline.org