Parent Brief

Promoting effective parent involvement in secondary education and transition.

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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).

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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 (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.

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?

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

Health and the IEP Process

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."

The American Academy of Pediatrics identifies four elements that are key to a successful transition:

1. Including health-care providers along with other service providers in transition planning;
2. Promoting opportunities for youth to be active in their own health-care decision-making;
3. Parental support for giving youth more responsibility and independence—striving to balance the need for safety with the adolescent's need to become an adult; and
4. Continuity between pediatric and adult health-care providers.

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?

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?

Home Living

- 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?
- 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?

Community Life

- 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?

Health Transition Goals and Objectives[1]

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.

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References:

American Academy of Pediatrics. (2002). Improving transition for adolescents with special health care needs from pediatric to adult-centered care. *Pediatrics*, *100*(8), 1304-1306.

Geenen, S., Powers, L. E., & Lopez-Vasquez, A. (2001). *Parents as partners: Understanding and promoting the multicultural aspects of parent involvement in transition planning*. Portland, OR: Oregon Health Sciences University, Center on Self-Determination.

Kelly, A. M., Kratz, B., Bielski, M., & Rinehart, P. M. (2002). Implementing transitions for youth with complex chronic conditions using a medical home. *Pediatrics, 100(6)*, 1322-1327.

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*

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.

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Access Parent Briefs and other NCSET materials online at: *http://www.ncset.org*. NCSET Parent Briefs and other transition information for parents can also be accessed via PACER Center's Web site at www.pacer.org.

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.

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