

Importance of Health in Transition Planning for Special Education Students: The Role of the School Nurse

Transition to adulthood is a process all youth face as they reach the end of their high school years. Transition may encompass a variety of activities, including learning to make one's own decisions, further education, job training, and moving from the family home. A crucial element of successful transition for all young people, but especially those with health issues or disabilities, is gaining the knowledge and skills they need to sustain their health and wellness. Good health is the foundation for success in the community and on the job. The transition process must support these students to learn about and become responsible for their health so they may become as independent as possible. Yet health is an aspect of the transition process that is often overlooked. Many students with special health care needs receive no health-related or other transition services through their schools.

“School nursing is a specialized practice of professional nursing that advances the well-being, academic success and life-long achievement and health of students. To that end, school nurses facilitate positive student responses to normal development; promote health and safety including a healthy environment; intervene with actual and potential health problems; provide case management services; and actively collaborate with others to build student and family capacity for adaptation, self-management, self advocacy, and learning.”

National Association of School Nursing, 2010

Health Services at School

Schools have three formal mechanisms to provide health services: the Individualized Health Plan (IHP), 504 Plan, and the Individualized Education Plan (IEP). While there is no legal requirement or funding to address transition from school to post-school life for either the IHP or the 504 Plan, there is a legal requirement for transition planning and services in the IEP. Many students with an IHP or 504 Plan could benefit from health transition planning similar to that required for students with an IEP.

- Individualized Health Plan (IHP) - Students who have a health need that affects them at school usually have an IHP. This document is written and overseen by the school nurse. For example, a student with a seizure disorder who is on medication may have a seizure action plan to be used if the student has a seizure at school.
- 504 Plan - Students who have a physical disability or chronic illness may qualify for accommodations under Section 504 of the Rehabilitation Act of 1973 which guarantees students with a disability equal access to education and school programs. The written plan for accommodations is called the 504 Plan. The school nurse is involved in the 504 Plan to the extent necessary to assure that the student's health needs during the school day are met. The IHP can become the 504 Plan for a student with only a health challenge. Examples would be a teen who uses a wheelchair may need extra time to

move from one classroom to another or a student with a hearing deficit may require special equipment or seating to ensure adequate hearing during class.

□ Special Education-Individualized Education Plan (IEP) - Students who qualify for Special Education must have an IEP which outlines their educational goals and the plan to achieve them. The IEP in effect when the student reaches the age of 16 has the additional requirement of creating and addressing post-secondary goals designed to prepare the student for life after high school. This plan is called the 'Transition IEP' and identifies transition services, activities and training that are needed for the student to meet his or her postsecondary IEP goals.

Health-related needs and goals are often inadequately addressed in the Transition IEP. However, lack of attention to long term self management of health can jeopardize other postsecondary goals for education/training, employment and independent living. A person who is not healthy is less likely to succeed in school or at work. A person who does not have self management skills for maintaining health is at a disadvantage in becoming more independent and succeeding in post-school activities. Youth with health issues or disabilities are more likely to stay well when they understand their health needs and have been trained and supported to work with their health care team to take responsibility for their health. Including health and medical goals in the IEP will aid transition by giving students an opportunity to learn about and take responsibility for their health.

Among IEP team members and school staff, the nurse is likely to have the most knowledge about students' health and can contribute health-related information for each step of writing the Transition IEP. In many districts, health-related needs are seen as ancillary daily needs that lie in the realm of the school nurse rather than long-term concerns that deserve the attention of the IEP team with the nurse as a key member.

In this paper, we will provide an overview of the Transition IEP requirements and offer step-by-step examples of how to include important health content in the Transition IEP. The importance of health transition is emphasized by a number of organizations serving youth and supporting statements from several regarding prioritization of health transition are included.

What is the IEP process? How is a Transition IEP created?

The Individuals with Disabilities Education Act, or IDEA, is the federal law that provides for Special Education. The Washington State rules for carrying out IDEA is called 'Rules for the provision of special education' and are contained in Chapter 392-172A WAC.

Under IDEA, an IEP must be written for every student in Special Education each year to address their needs and services for the year. The IEP in effect the year the student turns 16 must also address transition to adulthood. The purpose of transition services is to build the capacity of youth and set the stage for success in life goals. The goal of transition services is to facilitate the student's advancement from school to post-school activities. Some programs initiate transition activities at age 14 recognizing the usefulness of starting such planning earlier. Although not required, it may be useful to consider transition services before age 16.

Health information can be useful in each of the six steps in the Transition IEP, either to facilitate progress in other areas (post-secondary education, community living, employment, etc.) or to provide guidance for health-focused goals. The six steps listed below will be discussed at length in the following section:

1. Conducting age-appropriate transition assessments
2. Writing measurable postsecondary goals
3. Identifying transition services needed to achieve the above goals
4. Writing the planned course of study
5. Coordinating services with adult agencies outside of the school program
6. Writing the annual IEP goals

Steps to Incorporating Health in the Transition IEP

1. Conducting Age-Appropriate Transition Assessments.

Assessment is the ongoing collection of data about the student's needs, strengths, preferences, and interests. The IEP team's assessment information may include grades, interest surveys, aptitude and psychological tests, SAT scores, and/or interviews with the student, family members, and school staff. The school nurse's role is to gather and share health-related data from available sources, which may include direct observation and assessment of the student; review of medical records; and interactions with the student, the student's family, school staff, and relevant community service providers. The IEP team collects this data and uses it, along with data from other team members, for writing measurable postsecondary goals. The student must be invited to attend any meeting at which assessments are considered and post-secondary goals are written.

The following are examples of health-related data for each of the four areas – needs, strengths, preferences and interests. (For questions to consider in identifying health-related needs, see Appendix 1, Health and Key Areas of Transition.)

Here are some examples of health-related needs:

- Maria depends on her teacher to remind her to do position changes.
- Paul forgets to take his midday medication.
- Paul doesn't understand his seizure disorder or how to describe it to others.

Here are some examples of health-related strengths:

- Paul and his parents have found age-appropriate books about seizure disorders at the public library and are reading them together.
- Maria can explain, "I have cerebral palsy because I didn't breathe right away when I was born. I use a wheelchair because I can't walk. I drive it by pressing a touch pad with my head. I need help getting dressed, eating, and drinking, but I know what I need and can tell people how to help me."

- Maria's pediatrician knows her well and is interested in helping Maria transition to an adult provider.

Here are some examples of health-related preferences:

- Maria likes to get advice from family members before she decides between options for health care treatments and procedures.
- Paul wants to be responsible for his own medications and treatments without being reminded.
- Maria wants to go by herself to interview potential adult providers, and she wants to choose her own doctor.

Here are some examples of health-related interests:

- Paul likes basketball and soccer and wants to continue with Special Olympics after graduation.
- Maria is interested in learning to cook foods that will keep her healthy and help her maintain a healthy weight.

2. Writing Measurable Postsecondary Goals.

The student's preferences and interests are then considered as the team writes measurable post-secondary goals. The goals should address the areas of education/training and employment. If appropriate, postsecondary goals should also address the area of independent living. Independent living skills are defined as skills or tasks that contribute to the successful independent functioning of an individual in adulthood in the domains of leisure/recreation, home maintenance, personal care, and community participation. Depending on the student, health issues can be important in each of these areas. Health issues are most often found in the area of personal care. Postsecondary goals must be measurable and must occur after the student graduates from school. This is a measurable postsecondary goal: "After graduation, Paula will receive training to take the bus so she can go to her doctor's office independently." "Paula will learn to use the bus system" is not a measurable goal.

Here are some examples of measurable postsecondary goals which may be related to health issues for these students:

- After graduation, Paul will enter an apprentice program to be a plumber's assistant.
- After graduation, Maria will enroll in a bookkeeping program at the community college.

3. Identifying Transition Services Needed to Achieve the Above Goals.

The IEP team identifies Transition Services that are needed to help students meet their postsecondary goals. Transition services, in the language of IDEA, are "a coordinated set of activities for a student with disabilities that is designed to be within a results-oriented process, focused on improving the academic and functional achievement of the student to facilitate their movement from school to post-school activities, and is based on the individual's needs, taking into account their strengths, preferences and interests." Transition services include instruction, related services (including school nurse services), community experiences, employment and other post-school adult living

objectives. If appropriate, the set of transition services also includes acquisition of daily living skills and provision of a functional vocational evaluation (WAC 392-172A-01190). Here are some examples of health-related transition services:

- Instruction
- Related services
- Community experiences
- Development of employment
- Acquisition of daily living skills (if appropriate)
- Functional Vocational evaluation
 - Instruction in use of a Smart Phone for reminders to take medications.
 - Instruction in explaining the student's disability to a new physician.
 - Work with the School Nurse to learn to read and understand the labels on her prescriptions.
 - Travel training on the public transit system for traveling to get monthly lab work.
 - Work with wheel chair vendor to learn how to troubleshoot problems.
 - Visits to medical center clinic to practice being on time for appointments.
 - Work with OT to increase independence at mealtime.

4. Writing the Planned Course of Study.

The Course of Study is the schedule of coursework for the remainder of high school. The Course of Study is defined as 'a multi-year description of coursework to achieve the student's desired post-school goals, from the student's current year to the anticipated exit year.' The main coursework related to health includes any health-related curriculum such as classes in general health, physical education, sexuality and reproduction education, nutrition, or life skills.

Here are some examples of instruction for the Course of Study:

- Maria will complete the regular education health course during her junior year.
- Paul will participate in modified physical education classes.

5. Coordinating Services with Adult Agencies Outside of the School Program.

Appropriate agencies are identified that address the community experiences in the student's Transition Services. Public or state agencies include the Division of Vocational Rehabilitation, the Division of Developmental Disabilities, WorkSource, disability student services at postsecondary educational institutions, and mental health services. A representative of any agency or program related to the student's post secondary objectives may be invited to the IEP meeting with the parent or student's permission. Here are examples of health-related needs that can be addressed by coordinating services with an adult agency:

- Paul will apply for Social Security Supplemental Security Income (SSI) and Medicaid health insurance when he turns 18.
- The Special Education teacher will contact the Metro Bus Training program to enroll Maria as a client. Maria will be trained to ride the bus so she can go to the doctor and shop for her prescriptions and supplies.

6. Writing the Annual IEP Goals.

The postsecondary goals in Step 2 are now addressed in specific steps. The postsecondary goals are reviewed to determine what the student can reasonably be expected to accomplish in the next 12 months. The hope is that skills can be taught and learned. If a skill needed for transition cannot be achieved, a plan is then developed to support the student in that area. The annual goals must include a timeframe and be specific, measurable, and results-oriented. Annual goals should include self-care and independent management of health conditions.

Here are some examples of health-related annual IEP goals:

- Maria will be able to explain to a peer how her disability affects the way she learns.
- Maria will be able to go to the pharmacy with an adult, meet the pharmacist, order refills of her prescriptions, and pay for them.
- Paul will arrange to meet and interview two potential adult health care providers.
- Paul will obtain a calendar and record his medical appointments and treatments for two consecutive months. He will then use the calendar as a reminder to attend the appointments.
- Maria will learn what to do when her wheelchair has a flat tire. She will participate in a practice situation of getting a flat tire while she is away from home.

Examples for the Transition IEP

1. Conducting Age-Appropriate Transition Assessments.

Needs:

- Paul forgets to take his midday medication.
 - Maria needs to transition to an adult healthcare provider by age 20.
- Strengths:
- Paul is eager to learn to take his medication to improve his seizure control.
 - Maria's pediatrician recognizes that it is important for Maria to transition to adult health care.
- Preferences:
- Maria wants to go by herself to interview potential adult providers, and she wants to choose her own doctor.

2. Writing Measurable Postsecondary Goals.

- After graduation, Maria will have a new adult health care provider and travel to appointments on her own.
- After graduation, Paul will attend an all-day plumber's apprentice program.

3. Identifying Transition Services Needed to Achieve the Above Goals.

- The Special Education teacher or designee will teach Paul how to set the alarm on his smart phone, and Paul will practice until he can set the alarm independently.

4. Writing the Planned Course of Study

- Maria will complete the regular education Health course.
- Paul will complete the regular physical education course with modifications for safety.

5. Coordinating Services with Adult Agencies Outside of the School Program.

- Paul will apply for Social Security Supplemental Security Income (SSI) and Medicaid health insurance when he turns 18.
- Special Ed teacher will help Maria register for bus training with the local transit service.

6. Writing the Annual IEP Goals.

- Paul will use his smart phone to remind him to take midday medication and will take his meds independently 3 out of 5 weekdays each week by the end of the school year.
 - Maria will identify and interview two potential adult healthcare providers by the end of the school year.

What do government agencies and professional organizations say about adolescent transition to adult health care?

“High school graduation traditionally signifies a time filled with many challenges and changes. It is a time anxiously awaited by students and parents, filled with hopes and dreams of successfully leaving high school and moving into employment and/or post-secondary education. Halpern (1992) has defined this transition as “a period of floundering that occurs for at least the first several years after leaving school as adolescents attempt to assume a variety of adult roles in their communities”.

Unfortunately for students with disabilities the “floundering period” often lasts for years, and in some cases, a lifetime. To ensure full implementation of IDEA and to help youth with disabilities and their families achieve desired post-school outcomes, NSTTAC helps each state build capacity to support and improve transition planning, services, and outcomes for youth with disabilities.”

The National Secondary Transition Technical Assistance Center (NSTTAC)

“Each individual child or youth with special health care needs is unique and has many of the same hopes and dreams we all do. Health is an essential component in pursuing those hopes and dreams. For some of us, health related issues are more challenging than for others. Whatever we can do to involve young people in understanding their health needs and participating in their own health care will help them in the pursuit of their hopes and dreams.”

Wisconsin Community of Practice on Transition, Practice Group on Health

The Healthy People 2010 HRTW/Transition Workgroup believes that ALL children deserve a future, to grow up and to be as independent in their lives and in their communities as possible. For many of our children and youth with special health care needs, this will mean employment, for others improved recreational and social

opportunities in their communities, and for ALL an improved or sustained health status as they age into and access adult health care delivery.”

10-year HRTW/Transition Plan for the Maternal and Child Health Bureau
Division of Services for Children with Special Health Needs

Teens and young adults with special health care needs should be able to:

1. Understand their condition and the treatment or intervention needed.
2. Explain their condition and needed treatment or intervention to others.
3. Monitor their health status on an ongoing basis.
4. Ask for guidance from their pediatric health care providers on how and when to make the move from pediatrics to adult care.
5. Learn about the systems that will apply to them as adults:
 - health insurance (private or medical assistance) and why it is important
 - Social Security
 - guardianship
 - power of attorney for health care.
6. Identify both formal and informal advocacy services and supports they may need to be as independent as possible while using trusted advisors/mentors.”

Maternal and Child Health Bureau of the US Department of Health and Human Services

The goal of healthcare transition is to maximize lifelong functioning and potential through provision of high-quality, developmentally appropriate health care services that continue uninterrupted as the individual moves from adolescence to adulthood. It is patient centered and its cornerstones are flexibility, responsiveness, continuity, comprehensiveness, and coordination.”

Healthcare transition facilitates transition in other areas of life as well, such as work, community, and school.”

The American Academy of Pediatrics, American Academy of Family Physicians, and American College of Physicians Consensus Statement of 2002

Ensure that all youth with special health care needs receive the services they need to make necessary transitions to all aspects of adult life, including adult health care, work, and independence.”

Healthy People 2010 Performance Core #6