

# Transition Planning for Students with Chronic Health Conditions



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## *Position Statement*

### **SUMMARY**

It is the position of the National Association of School Nurses (NASN) that all children with chronic health conditions should receive coordinated and deliberate transition planning to maximize lifelong functioning and well-being. Transition planning refers to a coordinated set of activities to assist students with chronic health conditions to begin in school, and then move from one school to another, from hospitalization back to school, and from the secondary school system into their next stage of life (Selekman, Bochenek, & Lukens, 2013). The registered professional school nurse (hereinafter referred to as school nurse) has the perspective and skills to provide care coordination and lead the planning team to address transitions for students with chronic health conditions.

### **BACKGROUND**

Increasing numbers of children with special healthcare needs and complex medical conditions attend school on a regular basis (American Academy of Pediatrics [AAP], 2008). According to Murphy and Carbone (2011), there are 10 million U.S. children with special healthcare needs. Advances in medicine and technology allow most children with chronic conditions to reach adulthood. Changes in healthcare delivery (e.g., reduced hospital stays and increased outpatient care) have shifted the burden of care to the community (Shaw & McCabe, 2008). For example, Lotstein and colleagues (AAP, 2013) identified that youth with type 1 diabetes are at an increased risk for poor glycemic control after transition from pediatric to adult care and need additional support with moving to adult care. In 2011, the AAP reported that transition planning has been uncertain, incomplete, or late; and the transfer of care has not been clearly planned.

Federal laws support transition planning for students with chronic health conditions by requiring schools to provide students with equal opportunity to participate in academic, nonacademic, and extracurricular activities.

- The Individuals with Disabilities Education Improvement Act (IDEIA), 2010 regulations, entitles students with disabilities and those who need specialized instructions to receive the services needed to have access to a free and appropriate education (FAPE) in the least restrictive environment. IDEIA has a limited set of recognized impairments and criteria. These impairments have an adverse effect on educational performance necessitating special education, specific to learning (Zirkel, Granthom, & Lovato, 2012).
- For those students who do not qualify for services under IDEIA, Section 504 of the Rehabilitation Act (1973) requires that reasonable accommodations be provided so that the student can fully participate in the educational experience.
- The Americans with Disabilities Act (ADA) (2008) prohibits discrimination based on disability.

Eligibility under Section 504 and the ADA equates to meeting three essential elements for the definition of disability, which includes (a) physical or mental impairment that (b) substantially limits (c) one or more major life activities (Zirkel, Granthom, & Lovato, 2012).

In addition to support provided by federal law, Lineham (2010) found that planning for timely and seamless transitions should be in place to avoid interruptions of students' access to the services needed to fully participate at school. Providing for the health needs of students with chronic health conditions and enabling them to have

access to the same educational opportunities as their peers have positive benefits (Wideman-Johnston, 2011). These benefits include enhancing their self-identity and increasing resiliency.

## **RATIONALE**

Transition planning includes coordinated, deliberate, and community-based strategies to ensure positive health and academic outcomes for the student with a chronic illness, disability or injury (Craig, Eby, & Whittington, 2011). The goal of transition planning is to maximize the student's health and academic experience. Communication between the healthcare provider and school is critical to raising awareness of the transition needs of the student and determining how to best address these needs (Glang et al., 2008). For example, when transitioning a child into the school system after a prolonged hospitalization for injury or illness, both the child and the school environment must be evaluated to identify services and accommodations needed for the student to fully engage in his or her educational experience (AAP, 2008). The transition planning for adolescents with special healthcare needs transitioning to adulthood includes the development of self-management and decision-making skills to foster active participation in maintaining his/her own health (AAP, 2011).

Transition plans for students with chronic health conditions should be developed for each planned transition in collaboration with the healthcare provider, parent/guardian, student, teachers, and other appropriate school staff. According to the AAP (2008), school nurses are positioned to take the lead in making these transition plans. These plans should identify, support, or promote access to needed services and resources both within and outside the school setting. Transition plans should focus on providing the needed accommodations and services to meet academic, social, and emotional needs; stimulate academic motivation; and promote adjustment to the school setting (Shaw & McCabe, 2008). The development and implementation of a transition plan can improve the quality of life for the child and his or her family by providing the support needed to promote student health and academic success. Individualized transition planning that is started with the healthcare provider prior to school entry empowers the parents/guardian to clarify the needs of their child and identify preferred strategies to meet those needs (Glang et al., 2008). In addition, the school and school nurse are better prepared to implement the transition plan in a coordinated and seamless manner.

It is important to address the following issues when transition planning with students that have chronic health conditions:

- Privacy of student health information -- "The *HIPAA* Privacy Rule allows covered healthcare providers to disclose PHI about students to school nurses, physicians, or other healthcare providers for treatment purposes, without the authorization of the student or student's parent. For example, a student's primary care physician may discuss the student's medication and other healthcare needs with a school nurse who will administer the student's medication and provide care to the student while the student is at school." (U.S. Department of Health and Human Services, 2008, p. 1).
- Transition plans must be individualized. Students with similar medical conditions may respond to and adjust differently as a result of temperament, comorbidities, stage of disease, family factors and social support (Shaw & McCabe, 2008).
- The school nurse should lead the school health team. Since school nurses often cover multiple schools, the school nurse may need to delegate nursing tasks when allowed by district policy and state law in order to implement the transition plan for a student.
- In accordance with state law, when nursing tasks are delegated to other members of the school health team, the school nurse remains accountable for the decision to delegate, for training the delegate and for providing ongoing supervision of the delegate (American Nurses Association [ANA], 2012; Kruger, Toker, Radjenovic, Comeaux, & Macha, 2009).

The role of the school nurse is essential in caring for children with chronic health conditions (Kruger et al., 2009). In order to effectively support transitions for students with chronic health conditions, school nurses should do the following:

- Be knowledgeable about applicable local, state and federal law;
- Maintain clinical competence to provide direct care and/or delegate care for children with chronic health conditions, injuries or disabilities;
- Develop a relationship with the student's healthcare provider and family to assure that the medical orders and resulting individual health plans are implemented correctly;
- Provide consultation and/or referral to the medical home and community resources (AAP, 2008);
- Identify needs across the coordination team for continuing education regarding chronic conditions (Kruger et al., 2009);
- Influence the development of policies surrounding chronic disease management and coordinated school health programs (AAP, 2008);
- Ensure that there is adequate communication and collaboration between the student and family, healthcare provider, school officials, and providers of community-based resources (AAP, 2008); and
- Ensure continuity, compliance and supervision of care for the child with a chronic condition or injury who attends school (AAP, 2008).

## CONCLUSION

The education system is greatly impacted by children with chronic health conditions. School nurses must advocate for meeting the healthcare needs and services that these children require. Effective transition planning is a shared responsibility of all professionals involved in the care of children with chronic conditions (Lineham, 2010). Transitioning -- whether at the time of beginning school, from school to school, school to adult life or between the hospital and school environment -- provides an opportunity for care coordination led by the school nurse.

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#### **Acknowledgement of Authors:**

Rita Baszler, BSN, RN  
Laura Rochkes, MS, BSN, RN, NCSN  
Rosemary Dolatowski, MSN, RN  
Irene Mendes, MEd, BSN, RN, PHN  
Barbara Yow, MEd, BSN, RN, NCSN  
Sarah Butler, MS, RN, CDE, NCSN  
Nina Fekaris, MS, BSN, RN, NCSN

#### **Acknowledgement of 2012 Issue Brief Authors:**

Debra M. Robarge, BSN, RN, NCSN  
Leigh Ann DiFusco, MSN, RN, CNOR  
Janice Selekman, DNSc, RN, NCSN  
Janet Bryner, BSN, RN, NCSN  
Kendra Selser, MHS, BSN, RN  
Leah Wyckoff, MS, BSN, RN, NCSN  
Georgene Westendorf, MPH, BSN, NCSN, CHES  
Robin Fleming, PhD, RN

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National Association of School Nurses  
1100 Wayne Avenue, Suite 925  
Silver Spring, MD 20910  
1-240-821-1130