

## Brief Transition Literature Summary

Drafted by Michelle Kempf-Weibel - Wisconsin

Policy and position statements provide general guidance for the transition process from the pediatric to the adult health care setting. In 2002, the American Academy of Pediatrics (AAP), the American Academy of Family Physicians and the American College of Physicians-American Society of Internal Medicine convened on the topic of health care transition for young adults with special health care needs. A consensus statement was published stating that the goal for transition includes “maximizing lifelong functioning and potential through the provision of high-quality, developmentally appropriate health care services that continue uninterrupted as the individual moves from adolescence to adulthood” (1).

Even with such statements, health care transitions remain elusive for many adolescents and young adults with special health care needs. In a National Survey of Children with Special Health Care Needs, only 15% of youth met the Maternal and Child Health Bureau’s core outcome for medical transitions (2). These core outcomes included the physician addressing the child’s changing needs in adulthood, the child having a plan to address those needs, and the physician discussing the transition to an adult health care provider (2).

Data have been collected from adolescent patients, adult patients, parents, and health care providers regarding the transition process for individuals with chronic medical conditions including cystic fibrosis, sickle cell disease, diabetes, spina bifida, cerebral palsy and other physically disabling conditions (3-10). Only a few studies explored young adult patient’s perspectives and lived experiences with transition (3, 7, 8).

Independent of the individual’s condition, these studies describe a number of barriers in the process of transition. The complexity of the condition, often indicated by the number of

health care providers used for care, was seen as a barrier for a successful transition because of difficulties finding adult specialists to match the ones seen in pediatrics (11). The complexity of the condition also related to finding affordable and high quality health care coverage or financing for the individual during the transition to an adult health care provider (3, 7, 8). Leaving a familiar setting and trusted health care provider can be a difficult experience (4, 6). Once one leaves a familiar setting, there are often concerns about the new health care provider's knowledge about the condition and ability to manage care (6, 8). Also, inclusion of the patient in discussions regarding transition, with recognition of readiness or preparedness, are important considerations in the timing of the transition process (4, 8, 11).

These same studies identified elements that improve the transition process. One factor was a positive or high quality relationship between the health care provider, the patient, and family members, which is a strong indicator for a successful transition (8, 11). Another factor for a successful transition was support from both health care providers and individuals who had gone through the process or were currently in the process (4, 7).

## **References**

1. A consensus statement on health care transitions for young adults with special health care needs. *Pediatrics*. 2002;110(6 Pt 2):1304-6.
2. Lotstein DS, McPherson M, Strickland B, Newacheck PW. Transition planning for youth with special health care needs: results from the National Survey of Children with Special Health Care Needs. *Pediatrics*. 2005;115(6):1562-8.
3. Palmer ML, Boisen LS. Cystic fibrosis and the transition to adulthood. *Soc Work Health Care*. 2002;36(1):45-58.

4. Soanes C, Timmons S. Improving transition: a qualitative study examining the attitudes of young people with chronic illness transferring to adult care. *J Child Health Care*. 2004;8(2):102-12.
5. Scal P, Evans T, Blozis S, Okinow N, Blum R. Trends in transition from pediatric to adult health care services for young adults with chronic conditions. *J Adolesc Health*. 1999;24(4):259-64.
6. Hauser ES, Dorn L. Transitioning adolescents with sickle cell disease to adult-centered care. *Pediatr Nurs*. 1999;25(5):479-88.
7. Westwood A, Henley L, Willcox P. Transition from paediatric to adult care for persons with cystic fibrosis: patient and parent perspectives. *J Paediatr Child Health*. 1999;35(5):442-5.
8. Reiss JG, Gibson RW, Walker LR. Health care transition: youth, family, and provider perspectives. *Pediatrics*. 2005;115(1):112-20.
9. Geenen SJ, Powers LE, Sells W. Understanding the role of health care providers during the transition of adolescents with disabilities and special health care needs. *J Adolesc Health*. 2003;32(3):225-33.
10. Luther B. Age-specific activities that support successful transition to adulthood for children with disabilities. *Orthop Nurs*. 2001;20(1):23-9.
11. Scal P, Ireland M. Addressing transition to adult health care for adolescents with special health care needs. *Pediatrics*. 2005;115(6):1607-12.
12. Betz CL, Redcay G. Dimensions of the transition service coordinator role. *J Spec Pediatr Nurs*. 2005;10(2):49-59.