



SOCIETY OF  
PEDIATRIC NURSES

## SPN Position Statement: Transition of Pediatric Patients into Adult Care

### INTRODUCTION/PROBLEM STATEMENT

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The Society of Pediatric Nurses (SPN) is committed to addressing the long-term biopsychosocial needs of adolescents and emerging adults. This includes adolescents with disabilities and/or special health care needs (ASHCN) as they prepare to leave the pediatric and child-centered systems of care and enter the adult-focused systems of care. During this transition from pediatric to adult care, pediatric nurses can help these emerging adults as they proceed with their own development to the extent possible in achieving the competencies associated with adulthood. Adolescent health issues have become more pressing as nearly 90% of ASHCN survive into adulthood (Ferris, Gipson, Kimmel, & Eggers, 2006; Quinn, Rogers, McCavit, & Buchanan, 2010; Reiss & Gibson, 2002; Scal & Ireland, 2005).

Research demonstrates improved transition models of care are needed to better prepare adolescents and emerging adults for the transfer to adult services (Betz, O’Kane, Lobo, & Nehring, 2015; Chu, Maslow, von Isenburg, & Chung, 2015; Prior, McManus, White, & Davidson, 2014). This position statement is designed as framework for pediatric nurses to provide comprehensive health care transition services based upon a family-centered, adolescent-focused and interdisciplinary framework of care. For many ASHCN, the transition from pediatric to adult health care is not well planned and often results in disruptions in care, preventable complications, and avoidable costs. Despite the need for continuous, coordinated care from a pediatric to an adult medical home, research findings demonstrate that ASHCN report that they did not receive needed transition support. (Betz, Nehring, Lobo, & Bui, 2013; Joly, 2015; National Med- Peds Residents’ Association, 2013). It is suggested that schools of nursing, healthcare institutions and community based health care programs wherein pediatric nursing care is taught and/or provided utilize this document as a resource to ensure that appropriate education, training, resources and effective staffing plans are provided to ensure the provision of quality, customer focused care for pediatric patients and their families.

### DEFINITIONS

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#### **Transfer of Care:**

Transfer of care refers to the dual process of locating and arranging primary, specialty and interdisciplinary health care providers who provide care to adolescents as their eligibility for services provided by pediatric providers ends.

#### **Health Care Transition:**

Health Care Transition (HCT) refers to the comprehensive services based upon an interdisciplinary framework of care that addresses the biopsychosocial needs of early adolescents (11-15 years of age), late adolescents (16-18 years of age), and emerging adults (18-25 years of age). This framework of services is utilized throughout the lifespan and intensifies in early adolescence to ensure adolescents and emerging adults learn the self-management knowledge and skills necessary to manage their daily treatment needs as independently as possible and become a literate health consumer. Comprehensive services include coordination of care that involves referrals to the service systems of education and training, employment,

community living, rehabilitation and advocacy.

## RATIONALE AND SUPPORTING INFORMATION

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Since 2002, a number of studies have examined both practice-based approaches and barriers to transition from the perspectives of pediatric and adult health care providers. This research has identified a range of barriers in facilitating the successful transfer of care and health care transition. Barriers include inadequate and delayed planning for transfer and transition; lack of formalized guidelines to direct provision of health care transition services including a written transition plan and portable medical summary; and insufficient health care transition resource materials. Other barriers identified include shortages of available adult providers, lack of providers' HCT knowledge about the planning process and transition and adult community-based resources; and lack of an identified person responsible for transition planning (Fegran, Hall, Uhrenfeldt, Aagaard, & Ludvigsen, 2014; Joly, 2015; National Med-Peds Residents' Association, 2013; Nehring et al., 2015; Reiss, Gibson, & Walker, 2005; Schultz, 2013; Speller-Brown et al., 2015; Young et al., 2009).

The transition to adult health care services for the adolescent or young adult both with and without special health care needs is a process that occurs over time with increasing emphasis during early adolescence. Many young adults who have transferred their care into the adult health care system have experienced barriers to care. These barriers include expectations of adult care, decreased provider familiarity with complex chronic conditions of childhood or adolescent and young adult development, and a lack of support around the access to specialty and community services (Cook, Siden, Jack, Thabane, & Brown, 2013; Fegran, Hall, Uhrenfeldt, Aagaard, & Ludvigsen, 2014; Reiss, Gibson, & Walker, 2005; Schultz, 2013; Young et al., 2009). Although many of these barriers can be attributed to differences between pediatric and adult health care, pediatric nurses can play an important role in addressing these barriers as they care for adolescents and emerging adults prior to, during and following the transition to adult care.

## POSITION and/or RECOMMENDATIONS

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Health care transition is a service model that involves three distinct yet integrated components of care: a) the period of Extended HCT Preparation; b) the Transfer of Care Period; and c) the period of Post Health Care Transition/Transfer of Care. Each period is an essential component of this service model and is integral to promoting successful health care transition outcomes for adolescents and emerging adults as they transition to adult care and adulthood. Extended HCT Preparation, beginning in early adolescence, refers to the long-term health care transition planning needed to assist and support the adolescent/young adult to become competent as is developmentally appropriate with self-management knowledge and skills and the acquisition of life skills. The Transfer of Care Period, occurring between ages 18 to 21 years, refers to the intensive effort directed to the transfer of care to adult care providers and resources. Post Health Care Transition/Transfer of Care addresses the recommendations to facilitate achievement of HCT outcomes, which include implementation of quality improvement and research efforts that are needed for evidence based practice and to contribute to the science of health care transition. As described below, these components of care, although focused in their objectives of care represent an integration of purpose and effort to effect optimal outcomes for adolescents and young adults and their families during health care transition.

### **Extended HCT Preparation**

The Society of Pediatric Nursing recognizes that in order to provide optimal transitional care from pediatric to adult care, there must be adequate preparation in the framework of services initiated prior to transition. This preparation involves nurses and interdisciplinary colleagues with the expertise in the comprehensive biopsychosocial needs of all adolescents as they move from pediatric focused care to emerging adult and adult provider systems. Concepts of autonomy, independence, self-determination, and self-advocacy are integrated into the principles of care.

1. HCT planning should be initiated well before the intensive period (beginning at 12 years of age) of planning, preferably in early adolescence.
2. HCT planning includes the adolescent/young adult, the family, the current healthcare team (Bridgett, Abrahamson, & Ho, 2015; Findley, Cha, Wong, & Faulkner, 2015; Joly, 2015).
3. HCT plans should be based upon a framework of care that incorporates health care transition best practices for the adolescent/family and emerging adult. This care should focus on the adolescent's interests, needs and preferences. The plan of care should also have measureable outcomes, benchmarks of achievement, and an interdisciplinary approach to care incorporating the nursing process; Benchmarks should be created based upon a detailed timeline, which may be unique for each individual adolescent and family (American Academy of Pediatrics [AAP] et al., 2011; Betz et al., 2014; Findley et al., 2015; Joly, 2016).
4. A formalized process of assessment based upon a HCT framework should be used as the basis for plan development. There are several assessment tools available that can be used to measure what has been referred to as transition readiness. The plan is expected to be fluid and responsive to the needs of the adolescent and emerging adult based upon continuous assessment of needs and readiness (AAP et al., 2011; Celona, 2015; Disabato, Cook, Hutton, Dinkel, & Levisohn, 2015; Ferris et al., 2015; Fredericks et al., 2010; Moynihan et al., 2015; Speller-Brown et al., 2015; Uzark et al. 2015; Wood et al., 2014).
5. A health care transition coordinator (HCTC) should be identified to provide leadership in the coordination of the transition. This HCTC will organize and guide the transition based on a predetermined policy unique to the patient population served, but structurally consistent with other specialty practices in the same organization (NCYP, 2013). The care coordinator must consider the clinical, psychosocial and educational needs of the adolescent (Hopper et al., 2014; National Institute of Health and Care Excellence, 2016; NCYP, 2013; Royal College of Nursing, 2013).
6. In the event there is not a designated HCTC available, the pediatric nursing staff will be well positioned to coordinate the care between pediatrics and adult health care. Ideally, one nurse can assume the role of the HCTC coordinating the preparation of patients to move into the adult care world. The coordinating care must include clinical, psychosocial, and educational needs and coordinate all for a successful transition (Betz & Redcay, 2003; Disabato et al., 2015; Hopper et al., 2014; Mauro, Powell, Major-Wilson, Sanchez, De Santis, & Friedman, 2015).
7. Emerging adults need to acquire the self-management knowledge and skills to ensure independence with daily treatment regimen as appropriate for their developmental level. The pediatric nurse plays a key role educating patients about their disease, and the self care skills required to maintain health and wellbeing including emergency preparedness as they transition to adult care (Disabato et al., 2015; Findley et al., 2015).
8. In addition to teaching personal care skills, the pediatric nurse should provide education for life skills necessary to successfully function in the adult health care setting, namely skills in communication, decision making, assertiveness, self-determination and advocacy (Findley et al., 2015; Hait, Arnold, & Fishman, 2006; Joly, 2015; Mannino, 2015).
9. The HCTC and/or the pediatric nursing staff should coordinate referrals for services to promote a successful transition, including but not limited to and as needed (Betz et al., 2015; Betz & Redcay, 2005; Disabato et al., 2015).
  - a. School based career planning and job training and placement programs
  - b. Post-secondary planning supports (i.e. Disabled Student Services, Department of Rehabilitation)
  - c. Housing
  - d. Transportation
  - e. Community Living Programs (i.e. recreational, social)
  - f. Health care coverage
10. The age of majority (meaning the age at which the adolescent has the legal authority to make decisions for care) needs to be considered for appropriate planning purposes. For the adolescent who has an intellectual disability and his/her family, there needs to be discussion about guardianship well before the age of majority occurs. This discussion should include information

about the need and rationale for guardianship, the types of guardianships available and resources available in the community to assist families in obtaining a guardianship (e.g. referrals to no or low cost guardianships).

11. During the period of health care transition, pediatric nurses should discuss with adolescents and their parents the changing dynamics of their relationship from the parent's role as primary caregiver and case manager to that of coach, consultant and/or organizational assistant and its implications.

### **Transfer of Care Period**

The implementation of this transfer of care should occur during the later adolescent period (between ages 18 and 21 years), and should begin when the emerging adult exhibits signs of readiness. The process of execution will begin prior to the transition to adult care, and the intensity of the execution process will increase as plans progress. Teaching provided to the older adolescent and emerging adult getting ready for transition will intensify during the execution process, to ensure that he/she is indeed ready to transition.

1. The professional Pediatric Registered Nurse is in a unique position to act as a liaison between the pediatric and adult practices. Pediatric nurses can provide resources, consultation and/or training, as requested for interdisciplinary providers and services in adult and primary care who may have limited training in the management of childhood-onset special health care needs (Disabato et al., 2015; Findley, Cha, Wong, & Faulkner, 2015; Hopper et al., 2014; Joly, 2016).
2. For adolescents with intellectual disabilities, the family should have by this point taken the steps to obtain power of attorney (POA), guardianship or needed services for the adolescent. The goal should be that the adolescent will be as independent as safely possible. He/she may require supports in some areas but be independent in others. This will need to be an individualized plan for each older adolescent based on specific limitations and capabilities.
3. All records are appropriately transferred to the adult primary and specialty care providers and agencies prior to the actual transfer of care. It is recommended that, if possible, a direct handoff between pediatric and adult providers should occur (Disabato et al., 2015).
4. The pediatric nurse needs to ensure that all the necessary referrals are made. Additionally, arrangements should be made for the ordering and provision of necessary equipment and supplies to prevent gaps in services.

### **Post Health Care Transition/Transfer of Care**

The recommendations in the previous sections addressing care prior to HCT and during the transfer of care are important so that successful outcomes can be achieved. These potentially can reduce untoward outcomes such as service discontinuities, emergency department visits and readmissions to children's hospitals as well as lack of access to transition and adult services and supports (McDonnell, Kocolas, Roosevelt, & Yetman, 2010). Although pediatric nurses do not generally provide direct care for young adults following the transfer of care, there are several important considerations to be addressed following the transfer to adult care to ensure successful outcomes.

1. Pediatric nurses should ensure that documentation has occurred in the pediatric records indicating that the transfer has taken place and young adults have connected with adult providers (Disabato et al., 2015; Got Transition & Center for Healthcare Transition Improvement, 2014; McManus et al., 2015; National Institute for Health and Care Excellence, 2016).
2. The young adult and family should be encouraged to continue to engage in ongoing involvement and communication with community, public health and school programs that may provide additional guidance and support around other areas of transition to adult services after the transition to adult health services has occurred (Findley et al., 2015).
3. Pediatric nurses should be involved in the development of quality improvement, evaluation and research projects exploring achievement of outcomes such as independence, self-management, adherence, quality of life, involvement in education, vocation and/or recreation, and social network formation as adults. Outcomes explored should be relevant to the patient population

services. Such work can provide an indication of the success of and areas of improvement for health care transition planning and implementation (Aldiss et al., 2015; AAP et al., 2011; Campbell et al., 2016; Celona, 2015; Disabato et al., 2015; Fair et al., 2015; Joly, 2015; Major et al., 2014; Maturo et al., 2015).

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