



# *Movin' On Up: An Innovative Nurse-Led Interdisciplinary Health Care Transition Program*

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## ABSTRACT

This article provides an overview of an innovative nurse-led interdisciplinary health care transition (HCT) model of care entitled *Movin' On Up* for adolescents and emerging

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adults (AEAs) with spina bifida (SB) that was originally implemented in 2011. The components of the HCT service model include an HCT nursing specialist, who is an advanced practice nurse; interdisciplinary health care transition plans based on the individualized needs of AEAs; an interdisciplinary HCT team that meets on a weekly basis; direct HCT services provided in the weekly SB clinic; and telephonic follow-up with AEAs, families, and providers. The characteristics of this nurse-led HCT program can be described as an integrated, interdisciplinary, and comprehensive model of care based on a life span approach. To date, a total of 210 AEAs with SB, ages 10 to 20 years, have been enrolled into the program. An important feature of this HCT service model is that it is self-supporting; it generates the revenue needed for sustainability and, unlike other HCT programs, is not reliant on extramural programmatic support. Other accomplishments of *Movin' On Up* include the development of a transfer protocol wherein 35 AEAs with SB have been supported in their transfer to adult care; implementation of a standardized process to ensure that service referrals to community-based services for postsecondary education, employment, training, and initiation of conservatorships are made; timely performance of evaluations; close tracking of needs and outcomes of self-management knowledge and skills instruction; and attention to equipment needs prior to transfer. *J Pediatr Health Care.* (2016) 30, 323-338.

## KEY WORDS

Health care transition, adolescents and emerging adults with special health care needs, advanced practice nursing

Acknowledgement of the health care transition (HCT) service needs of adolescents and emerging adults (AEAs) with special health care needs (SHCNs)

has generated considerably more attention during the past two decades. More than 20 years ago, HCT was the featured topic in the 1989 Surgeon General's Conference *Growing up and Getting Medical Care: Youth with Special Health Care Needs* (Koop, 1989). At that time, Surgeon General C. Everett Koop emphasized the importance of addressing the long-term health, social, and developmental needs of AEAs with SHCNs who survived into adulthood. Since that time, the numbers of AEAs with SHCNs who reach adulthood has steadily risen to approximately 750,000 annually (Scal & Ireland, 2005). The increasing numbers of AEAs with SHCNs who advance into adulthood and transfer to adult care have created service and systems challenges that were predicted by clinical experts, advocates, and policy makers long ago.

Widespread international efforts are now under way to implement and test the effectiveness of HCT service models. Understandably, the science and practice of HCT are in the seminal stages of development.

The body of HCT literature has been heavily influenced by the pediatric medical model of care. In contrast, the model of HCT services described here is based on an advanced nursing framework of care, an approach that incorporates an interdisciplinary framework of services (Betz, 2013). This article presents an overview of this nurse-led interdisciplinary model of care that was originally implemented in February 2011. To date, 210 AEAs with spina bifida, ages 10 to 20 years, have been enrolled in the program, and 35 emerging adults have aged out of the program and had their care transferred to providers of adult-focused health care. An important feature of this HCT service model is that it is a self-supporting, revenue-generating, and sustainable HCT program that is not reliant on extramural programmatic support.

### **MOVIN' ON UP FRAMEWORK OF CARE**

The development of this HCT service model was based on the accepted principles of health care transition best practices and Health Care Quality and Outcomes Guidelines for Nursing of Children and Families (American Academy of Pediatrics, American Academy of Family Physicians, & American College of Physicians–American Society of Internal Medicine, 2005; American Academy of Pediatrics, American Academy of Family Physicians, American College of Physicians, Transitions Clinical Report Authoring Group, Cooley, & Sagerman, 2011; Betz, 2013; Betz, Cowell, Lobo, & Craft-Rosenberg, 2004; Craft-Rosenberg & Krajicek, 2006; Craft-Rosenberg, Krajicek, & Shin, 2002) and, more recently, further refined based on the Health Care Transition Research Consortium Health Care Transition Model (HCTRC HCT; Betz et al., 2014). Our previous experience with the implementation of the Creating Healthy Futures model of care (Betz & Redcay, 2002, 2003, 2005) and the testing of the

Transition Preparation Training Program (Betz, Smith, & Macias, 2010) were instrumental in the development of this HCT service model as well.

This article will provide a description of this model beginning with an overview of the *Movin' On Up*<sup>1</sup> HCT service model, including an explanation of the model components. This overview will be followed by a description of the model characteristics that exemplify its innovations compared with other HCT models currently reported in the literature. Discussion of the service adjustments made and lessons learned will follow. The article will conclude with current and future efforts to generate evidence by testing the effectiveness of this model, as well as other areas of inquiry pertaining to the process and provision of HCT services.

### **MOVIN' ON UP HCT SERVICE MODEL COMPONENTS**

*Movin' On Up* is composed of several components of care that are innovative, some of which are unlike other HCT service models reported in the literature (Betz, 2016). The components of this model support the practice philosophy that HCT is a long-term, continuous, complex, and coordinated process of care (Figure 1). The *Movin' On Up* model is composed of the following organizational components: (a) HCT nursing specialist; (b) interdisciplinary health care transition plans; (c) an interdisciplinary HCT team; (d) direct HCT services; and (e) telephone follow-up with AEAs, families, and providers. The components are described in the following sections and depicted in Figure 2.

#### **HCT Nursing Specialist**

The HCT nursing specialist performs as the service coordinator for *Movin' On Up*. The service coordinator role was originally reported in an early period of model development (Betz & Redcay, 2003). This role has since been adapted for this population of AEAs with spina bifida (SB) and related disabilities who receive care from an outpatient SB speciality clinic in a pediatric regional medical center located in an urban area of a Western state. The role responsibilities have changed considerably since the original model; however, the elements of the role remain essentially the same: assessment, coordination, and referral to interdisciplinary and inter-agency services; ongoing AEA monitoring and consultation pertaining to HCT planning; and evaluation of HCT care and AEA outcomes. The most significant changes of the role pertain to the ongoing provision of HCT services during the weekly SB clinics, as delineated in Box 1, and the coordination of weekly HCT interdisciplinary team meetings.

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<sup>1</sup>A naming contest was held wherein adolescents who received services through this program submitted suggestions to the naming committee. *Movin' On Up* was the name selected by the committee.

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