

COCWD TRANSITIONS INITIATIVES

Adolescent Transition and the Transfer to Adult Care: Changing from Drift to Direct Planning

With reasonable biologic and psychological certainty, most adolescents eventually transition to adulthood. There is much less certainty about the manner in which pediatricians support this transition, particularly for children with special health care needs (CSHCN). Transition planning, when present at all, can be inexplicit, incomplete, or late, and in some instances the transfer of care to an adult medical home and to adult specialists involves more of a drift away from pediatric care rather than a clearly planned and executed hand-off. And, while transition planning for CSHCN may demand and receive some attention, such planning rarely occurs for typical adolescents. Teens may become eligible to vote, attend college, or even go to war with little knowledge of health insurance, preventive health care, immunizations, or even their own personal health history. Transition planning as a part of high quality primary pediatric care should begin by age 14 and conclude with youth who are their own guardians entering an adult health care model at age 18. The basic process is important for all youth though those with special health care needs may require a more complex transition plan with greater coordination of care.

It has been 8 years since the AAP's consensus statement on transition was published. This statement provided foundational guidance for transition-related care processes that include care planning and information exchange, for professional education and certification, and for insurance and reimbursement reform.¹ Nevertheless, the 2005-06 National Survey of Children with Special Health Care Needs found that only 38% of CSHCN received anticipatory guidance about transition and 41% received the services necessary to transition to all aspects of adult life.² The AAP Periodic Survey of Fellows #71 in 2008 found that 62% of pediatricians believed that transition planning need not begin until after age 18 and less than 50% of pediatricians assist patients and families with finding an adult primary care medical home or adult specialty care providers.³ Adult primary care internists have clearly articulated their concerns about accepting young adult patients with special health care needs. They feel they lack training in congenital and childhood-onset conditions and worry about access to adult specialists and to adequate reimbursement.⁴

Inadequate or delayed transition planning for American youth results from the interplay of multiple factors. Typical youth often leave home or community for a variety of post-secondary school destinations (college, military service, jobs). Those who are healthy often leave the health care system altogether until a new health care need arises forcing the individual to either return to their pediatric care provider or find a new one in the adult health care world. For youth with chronic conditions or disabilities, years of continuity and support from a pediatric medical home may be difficult for both parents and youth to leave behind. Pediatricians may experience obstacles in identifying willing and appropriate adult physicians to whom they can feel comfortable transferring care, and they may also feel reluctant to sever long-standing, often emotional bonds with a youth and family.

Preparing youth for the transition to an adult health care model remains an important strategic priority for the AAP. The COCWD Executive Committee and staff are leading the transitions initiative, which is funded through the AAP's National Center for Medical Home Implementation (cooperative agreement between the AAP and federal Maternal and Child Health Bureau) and the COCWD. The ultimate goal of this initiative is to establish implementable recommendations and tools to help pediatricians support the transition of their patients to adulthood and the transfer of their care to appropriate adult models.

In June 2008, a Transitions Advisory Meeting, chaired by Dr. Carl Cooley and Dr. Paul Sagerman, met to review and advise the AAP on the development of a new, multi-phase transition initiative. From that meeting, a Transitions Clinical Report Authoring Group (TAG) was assembled. The TAG was charged with leading the first phase of the new transitions initiative—to develop a clinical report to help pediatricians ensure that youth continue to receive high quality, developmentally appropriate health care services following their transitions to adulthood. Subsequent phases of the transition initiative related to payment, training, health information technology, and outcomes research will utilize this clinical report as a touchstone. The American College of Physicians and the American Academy of Family Physicians have provided representatives to the TAG and have expressed interest in co-authoring the transition clinical report. The report is nearly ready for review by stakeholders within and outside of the AAP prior to publication. The report will provide explicit, implementable guidance to the primary care medical home using an algorithmic format addressing activities during office visits between 12 and 18 years of age. References to useful tools and templates will be provided. The clinical report addresses transition planning for all adolescents, but also provides a generic, but detailed pathway for CSHCN. It will provide a useful framework for the future development of more specific transition planning guidance related to individual chronic conditions and disabilities.

As the clinical report is being developed, ongoing educational topics focused on transitions are being offered at the Academy's National Conference and Exhibition (NCE) each year. At the October 2009 NCE, the following session was offered: "Walking the Transition Talk: Two Models that Work" and transitions-related topics have been accepted for presentation at the 2010 NCE.

Submitted by W. Carl Cooley, MD, FAAP

1. American Academy of Pediatrics, American Academy of Family Physicians, American College of Physicians, American Society of Internal Medicine. A consensus statement on health care transitions for young adults with special health care needs. *Pediatrics*. 2002;110(6):1304 - 1306.
2. Kane DJ, Kasehagen L, Punyko J, Carle AC, Penziner A, Thorson S. What factors are associated with state performance on provision of transition services to CSHCN? *Pediatrics*. 2009;123(Supplement 4):S375 - S383.
3. American Academy of Pediatrics. Periodic survey of fellows no. 71. Chicago: American Academy of Pediatrics; 2008.
4. Peter NG, Forke CM, Ginsburg KR, Schwarz DF. Transition from pediatric to adult care: internists' perspective. *Pediatrics*. 2009;123(2):417 - 423.

Special issue on Youth Health Care Transition: International Journal of Child and Adolescent Health 2010;3(4)

This is a call for papers dedicated to the subject of health care transition for youth and young adults, which will be published in 2010. We welcome papers from a wide range of professional perspectives and clinical areas. The papers should address some aspect of the process of transition from child-centered health or rehabilitative systems to adult-centered health or rehabilitative systems. We particularly seek translational work evaluating the transition process, testing innovative programs to support transition, or assessing transition outcomes for different populations of youth and young adults. We also want to encourage young investigators from different countries to describe the current state of health care transition experiences around the world. The articles may focus on the transition experience of populations defined by a particular condition or across conditions. Other populations of interest are youth with developmental disabilities, in foster care, or in the juvenile justice system.

Special issue editors/guest editors for this issue will be: David Wood, University of Florida (david.wood@jax.ufl.edu); John Reiss, University of Florida, (jgr@ichp.ufl.edu); Maria Ferris, University of North Carolina (maria_ferris@med.unc.edu); and Linda Edwards, University of Florida (linda.edwards@jax.ufl.edu). Articles are due April 1, 2010 and should be submitted to Dr. Wood as email attachment (Rtx or doc file). The articles should comply with the requirements located here: <http://jmerick50.googlepages.com/IJCAH-Leaflet.pdf>.

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