

# **Transitions to Adulthood for Individuals with Genetic Conditions: Model Action Plan**

Health Care Transition is “the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented health-care systems” (Blum et al, J Adolesc Health 1993; 14(7):570-576). It is composed of two key elements: 1) preparation for adult health care and a healthy adulthood, and 2) transfer of care, if appropriate. The goals of transitions are “...to optimize health and facilitate each young person’s attaining his or her maximum potential” (J Adolesc Health 2003; 33:309-311) and to allow individuals to “receive the services necessary to make transitions to adult life, including adult health care, work, & independence” (MCHB).

Transitions to adult health care can be even more difficult for individuals with special health care needs. There can be many different barriers to transitional care, including insurance issues, adolescent and family attitudes, and even unwillingness of the provider to transfer care. Transitional health care is also complicated by the fact that many “childhood conditions” are becoming “adult conditions” as progress in medical care has increased survival and decreased mortality, as seen in the increased lifespan of individuals with Down Syndrome and Cystic Fibrosis. There are also unique issues for transitions to adult health care for children and youth with genetic conditions. For example, most geneticists trained in pediatrics, and often there are no adult genetic clinics to transition to. In addition, many genetic conditions have adult-onset problems, although the natural history is unknown or not well documented for most rare genetic conditions.

*In order to address these issues, we are recommending the following core knowledge and action steps for genetic professionals:*

## **Core Knowledge**

1. Understand the importance of transition from child-oriented to adult-oriented health care
2. Understand the steps needed at different developmental stages and have the skills to facilitate the transition process
3. Know if, when, and how to transfer patient care

## **Steps for Successful Transitions**

1. Identify a health care transitions “lead,” a healthcare professional who assumes responsibility for current and future health care planning, as well as addressing the individual’s challenges of transition. This could be a genetic professional, a primary care provider, or another health care provider actively involved in the individual’s medical care.
2. Identify core knowledge and skills sets that are developmentally appropriate for the individual, provide this information to parents, and assess progress. Key components can include:
  - Gaining an understanding of one’s health condition
  - Taking responsibility for one’s medication and knowing why it is needed
  - Talking directly with health care providers
  - Learning self-care for one’s health condition

- Keeping a record of one's medical history.
- 3. Generate and keep up-to-date a medical summary that can be readily understood by other members of the medical community. Provide this summary to the primary care provider and to other health care professionals as appropriate, including if the individual transitions to an adult clinic. This summary should include recommendations for monitoring needs and discussion of natural history of the condition (if known) to anticipate changing medical needs.
- 4. Create a written health care transition plan regarding long-term care with the young person when appropriate and family between ages 14-16. This plan should include what services are necessary, who will provide them, and how they will be financed.
- 5. Assist with referrals to specialists as needed, and provide information about resources for advocacy, housing, working, and government programs as needed.
- 6. Work to secure affordable and continuous health insurance or disability coverage.

### **What the ACMG Can Do to Promote Successful Transitions**

1. Raise awareness about health care transitions in the genetics community. Specific actions could include:
  - Presenting at national meetings
  - Developing a position statement
  - Posting materials, resources, and information sheets on the ACMG website
2. Provide specific guidelines to enhance transitions to adult health care for individuals with genetic conditions
3. Advocate for funds for research on the adult consequences of "childhood" disorders so that future medical needs can be better anticipated
4. Provide new mechanisms for funded research on the natural history of genetic disorders