As the population of adolescent and young adults with chronic illnesses and disabilities continues to grow, an increasing emphasis will be placed on enhancing health care transitions from pediatric- to adult-oriented care settings. Greater attention will also be given to the critical role that physicians and other health care providers play in facilitating the transition of these individuals in non-health care domains. Specifically, providers should be aware of existing legislation and available resources that might aid the transition process in the areas of education, vocation, and independent living.

Such a focus is particularly necessary given the relatively poor outcomes of individuals with special health care needs in these domains. Data show that approximately 20% of individuals who have disabilities drop out of high school—more than twice the rate of their non-disabled peers.1 Similarly, it is estimated that 35% of people with disabilities are working compared to 78% of those without disabilities.1 Lastly, it has been reported that individuals with disabilities are twice as likely to worry about not being able to care for themselves or being a burden to their families.1

There has been significant legislation enacted since the early 1970s to address the educational needs of children, adolescents, and young adults with disabilities. Beginning with the Education of All Handicapped Children Act (EAHCA) of 1975 through the Individuals with Disabilities Education Act (IDEA), most recently amended in 2004, Congress has made provisions to enhance the educational opportunities of individuals with disabilities and assist in their transition to a maximally productive and rewarding adult life.

The EAHCA was instituted to assure free, appropriate public education to disabled children in all states.2 This legislation also established the standard of devising an Individualized Education Program (IEP) for every child receiving special education, with provision of services to extend through age 21. The IEP is developed through collaboration among students, parents, teachers, and administrators to organize school-based educational supports and services with the long-term vocational and professional goals of the student in mind. The IDEA mandates that educational transition planning must begin no later than age 14 and be in action by age 16, with a specific member of the IEP team assuming responsibility for each transition.3 Furthermore, the IEP transition plan must include goals for employment and adult living after high school and attempt to link individual students to community resources and agencies that might foster successful attainment of these goals.

For post-secondary education, the 1990 Americans with Disabilities Act (ADA) legislates that individuals may not be denied admission to post-secondary school based solely on the presence of a disability if they otherwise meet essential admission criteria.4 It further mandates that schools provide academic adjustments and supports (such as sign-language interpreters and extended time for testing) appropriate to an individual’s disabilities as long as these adjustments do no result in undue financial or administrative burden to an institution.

The role of the physician as defined through this legislation is merely to provide the diagnosis and evaluation of the disability in facilitating access to mandated educational supports. However, the health care provider has an important opportunity to advocate for the patient during this transition process by understanding relevant legislation, being aware of available community resources, and offering guidance when appropriate.

As referenced, young adults with special health care needs (YASHCN) are more likely than their healthier peers to have difficulty finding employment despite the fact that the majority of these individuals would like to work. Although this is attributable in part to physical and developmental limitations resulting from the individual’s underlying medical condition, other factors might also contribute. For example, supplemental security income (SSI) has historically restricted employment, thereby discouraging self-reliance through work. To address this, the Centers for Medicare & Medicaid Services created the “Ticket to Work Incentives Improvement Act of 1999,” which was enacted to allow patients to work while continuing to receive SSI and associated Medicaid benefits.5 Individuals enrolled in the “Ticket to Work” program are encouraged to seek assistance from state-run vocational rehabilitation agencies in the areas of career counseling, vocational training, etc.
ployment searches, and education regarding self-employment and telecommuting opportunities. Individuals might also be linked with a federally qualified Employment Network (EN) that can aid those with a disability in developing an individual work plan that outlines the individual's employment goals and the ways in which the EN can provide assistance. These agencies can be linked to children with developmental disabilities during the annual review of the IEP transition plan at school. Additionally, to further support the transition of YASHCN, it is imperative that providers collaborate early in the transition process with social work service providers who are familiar with these programs and can provide support to these individuals and their families as they consider future vocational goals.

YASHCN are likely to face many challenges as they attempt to transition to independent living. In part due to physical and intellectual impairments, these young adults may be unable to live safely and comfortably without the assistance of others. Limitations in income and options for transportation may additionally result in continued dependence on family members. In turn, family members are more likely to suffer financial hardship, thereby restricting available resources for on-going support. Given these obstacles, individuals should be aware of legislation and resources that facilitate independent living. As concerns financial assistance, patients and their families should inquire early in the planning process about their eligibility for SSI and Social Security disability insurance, realizing that eligibility standards for adults are not identical to those for children younger than age 18. In regard to housing, the Fair Housing Act of 1968 prohibits discrimination in the sale, rental, and financing of dwellings and other housing-related transactions based on the presence of a disability. Additionally, the ADA has provisions that allow for individuals, at their own cost, to make reasonable structural modifications to units and public common areas in a dwelling when those modifications may be necessary for a person with a disability to have full enjoyment of a dwelling. When necessary, referral to a legal expert to assist in the application of such legal rights may be helpful in achieving independent living. Individuals should also consider consultation with their local Center for Independent Living, which is a community-based, non-residential non-profit agency designed and operated by individuals with disabilities to assist others with disabilities in independent living skill training, peer counseling, and provision of information and referral services.

Early collaboration with social work service providers who are familiar with such legislation and community services is critical in all domains. Social work service providers may also be able to assist patients and their families in determining eligibility for a home-health attendant or homemaker services, adaptive medical equipment, assistive technology, family respite services, and transportation services.

In planning for the transition of YASHCN, health care providers need to consider both health care and non-health care domains. The challenges of transition can be very stressful to patients and their families. By addressing these challenges early in the process, engaging in on-going discussions about long-term goals for education, vocation, and independent living, and collaborating with social work service providers, legal health experts, and relevant community agencies, health care providers can promote a medically safe transition of care in all aspects of life.

References


