

Tribulations of transition care for the developmentally disabled

In his excellent review of the remarkable change in medical advances in the last millennium, Donaldson recounts the impressive evolution from epidemics of communicable diseases to the rise in chronic disease.¹ This phenomenon is apparent in the great increase in survival rates of children with developmental disabilities. Medical advances now account for the fact that over 90% of all children with disabilities are expected to live beyond twenty years of age.² The result of this medical progress is that 'the population of adolescents and young adults with chronic conditions is growing faster than our ability to provide age-appropriate care for them'.² It is estimated that the average pediatric specialist will have one in ten of their patients with a 'chronic, activity limiting condition'.³

According to Tuffrey, approximately 70% of persons with cerebral palsy will live to adulthood, as well as 50% of children with spina bifida, and 25% of boys with muscular dystrophy.⁴ Furthermore, the prevalence of chronic neurological conditions in ages 10 to 24 years per 1000 population includes epilepsy 5.1, hearing impairment 26.6, visual impairment 18.7, and moderate to severe learning difficulties 13.1.⁵

Providing transition of medical care for this patient population has not been addressed in countries with advanced medical programs. In the American and Australian systems private medicine is the norm. In the UK, a publication of the Royal College of Paediatrics and Child Health Services for Adolescents is soon to be issued, addressing the needs of adolescents. It has been suggested that adolescents should be seen without their parents before transfer, in an effort to promote a more independent relationship with their doctors to prepare them for future adult physician contact. Also, the family should be introduced to the concept of transition early and future medical care will of necessity need to be more appropriately provided by practitioners for adults.

A consensus statement on health care transitions for young adults with special health care needs was published in 'Pediatrics' in December 2002. Critical elements suggested include: identification of an appropriate health care professional; development of care knowledge and skills necessary to provide appropriate care; establishment and maintenance of a concise medical record; creation of a written health care transition plan by age 14; provision of uniform guidelines for primary as well as preventative care; and the greatest challenge in the US, the assurance of 'affordable, continuous health insurance coverage'.⁵

In the UK there are three main models for transition medical care: transfer from a pediatric to an adult specialist; primary care provided by a general practitioner; and the third option, primary care from a generic adolescent health service. According to Tuffrey there are few such clinics in the UK; in addition it is important to provide for transfer to in-patient services.⁴ Equally important is the issue of assimilating the young adult with disabilities into

adult society. The National Longitudinal Transition Study of Special Education Students in the US reveals that students with disabilities who enrolled in vocational technical education remained in school longer, had better attendance, attended post secondary vocational education, and were more likely to have a job two years later than those who had not enrolled.³

The consensus statement on health care transition which was published in 'Pediatrics'⁵ includes four additional articles which review in detail the various obstacles we face as clinicians in establishing comprehensive care for the aging population of patients with disabilities. The financial implications of this health issue are enormous. The US Congress has just made a major revision in the adult Medicare program which has gained wide press coverage. White noted that currently in the US the special health care needs of persons with disabilities are covered by Medicaid which reimburses between 58.3% and 72% of the Medicare reimbursement for the elderly which is considered by many to be insufficient.⁶ It is clear that the medical community as well as the government agencies must address this dilemma which has emerged in the last thirty years as the result of advances in medical care for the population of those with disabilities. All of us should become advocates for the proper transition of medical care for our patients with disabilities. In the words of Samuel Johnson 'A decent provision for the poor is the true test of civilization'.⁷

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