

INTRODUCTION

In the past many chronic pediatric conditions have resulted in early mortality and thus patients have not required health care as adults. As a result of improving technology, many patients with chronic pediatric conditions are now living well into adulthood. The adult health care system, however, has in the past not been ready and, in many instances, unwilling to take on these patients because of the lack of knowledge of the disease. Patients themselves have been reluctant to move into the adult health care model because they have had to give up the team approach and the multiplicity of services that have typified pediatric care. Nonetheless, staying in the pediatric setting robs them of needed independence, in many instances, and appropriate sub-specialty care by those familiar with adult medical issues.

This manual is intended as a guide for health professionals to establish a new health care delivery system for transitioning adolescents with chronic illness to adult health care. The manual is based on the experience of a cystic fibrosis team in a hospital for children and a department of internal medicine, section on pulmonary disease (in collaboration with other appropriate hospital departments) in developing a model of care that fostered the successful transfer of patients from one program to the other. While the experience was with patients with cystic fibrosis, the process for developing the model and the model itself has broad application to a variety of chronic diseases,

Historically, there have been a number of issues that have made it difficult to develop a successful delivery system model that leads to a smooth transition to adult health care for chronically ill adolescents. These patients have often had difficulty finding an adult health care setting where professionals are knowledgeable about their pediatric conditions and where the model of care is one that provides the level of support they have received in pediatric settings. Within both the pediatric and adult care setting, there are a number of financial complications that may make it difficult for pediatricians to transfer their patients or for adult care givers to want to assume their care. Patients themselves may find that there are differing financial implications for them, depending on the setting of care. Finally there has been a need for information about how to help patients and their families successfully negotiate the transition from childhood to adulthood within the health care system. Health care professionals wishing to embark on the process of molding the health care system to support successful transition need to consider all of these issues as they work towards that goal. This manual will help you systematically address these issues as you plan and execute your own approach to amending the health care system to support the smooth movement of adolescent patients into adulthood.

The care of patients with chronic pediatric conditions that persist into adulthood is generally highly specialized and complex. Most receive care in special centers or programs located in tertiary care facilities for these conditions. Often primary care for total health needs is provided in these centers rather than within the patient's own community. This approach can be a problem for both the adolescent and the adult patient. Typically the movement to adult care within these specialized settings has not proceeded smoothly because of the high degree of specialization within each section of the tertiary setting. This manual focuses on addressing the issues within those specialized settings, although always with an eye to the continued need for communication between the primary caregivers in the community and professionals in the tertiary center. The need for developing adequate primary care is an important one but beyond the scope of this manual

There are several assumptions underlying the development of this manual and the project on which it is based. Understanding these assumptions and Considering whether you can accept and support this view of care is undoubtedly important to your successful use of the manual as a road map. Successful transition requires the strong belief in certain basic premises. Our ten basic beliefs are:

- 1. Many chronic, congenital, genetic handicaps or diseases can no longer be considered exclusively "childhood diseases."**
- 2. Adolescents and adults with chronic "pediatric diseases are entitled to achieve independence and self-sufficiency.**
- 3. Because of its intrinsic nature and the milieu in which its activities take place, the pediatric care team is not entirely successful In achieving Independence for adult patients.**
- 4. The team approach Is an essential part of the care of chronically ill patients regardless of their age.**
- 5. Patients, particularly adults (and older adolescents), can adapt to a new health care system In a positive manner provided this system fulfills their needs.**
- 6. The adult health care system and adult caregivers are perfectly able to provide quality care to these adolescents/young adults with appropriate training in the area In question.**
- 7. Transition, transfer and change should be offered as an option and not Imposed upon patients.**
- 8. The leaders and the members of the adult and pediatric team must believe in the concept of transition, strive for excellence In patient care, and project a positive image of transition to patients and their families.**
- 9. The members of the pediatric and adult teams must be willing to recognize their own limitations and be willing to, learn from each other.**
- 10. Internists must gain the patient's confidence in the old fashioned way; they must earn it.**