

SOCIETY FOR ADOLESCENT MEDICINE

Transition from Child-Centered to Adult Health-Care Systems for Adolescents with Chronic Conditions

A Position Paper of the Society for Adolescent Medicine

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Definition/Introduction

Transition is defined in this paper as the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented health-care systems. Transition from such child-centered to adult health-care systems is important for *all* teenagers, healthy or ill. The purpose of *this* paper, however, is to address transition issues faced by the teenagers and young adults with significant chronic illness or disability. The optimal goal of transition is to provide health care that is uninterrupted, coordinated, developmentally appropriate, psychosocially sound, and comprehensive. While we can define the concept and goals of transition, there is simply too much that is not known about the process. Data suggest that youth with severe chronic impairments experience difficulty making the transition to the adult health system. We do not know, however, which model programs are effective and which are not; we do not know which models match best with which chronic condition or levels of severity; and we do not know if health status actually improves as a result of a formal transition program. In short, little or no evaluative data exist that demonstrate if transition programs make a positive difference in the lives of

adolescents. There is, however, a critical need to increase the *study* of transition and to evaluate the various program models.

Historical Perspective

The fact that transition is an issue at all is a product of a new and remarkably successful age in medical science. A generation ago, few children with severe chronic illness or disability survived to age 21 years. Issues of transition from pediatric to adult health care, consequently, were infrequent. Significant advances in medical science, practices and technologies have changed that dramatically (1). Currently, more than 85% of children with chronic conditions survive to adulthood (2). These high rates of survival mean that increasing numbers of adolescents confront the issues, questions, and barriers of transitional care. In addition, the shift from institutional to community-based, family-centered care, has increased the importance and public recognition of transition (see Table 1).

The basic groundwork on transition was laid at a national invitational conference held in Minnesota in 1984: "Youth with Disability: The Transition Years." Five years later, Surgeon General C. Everett Koop convened a second conference: "Growing Up and Getting Medical Care: Youth with Special Health Care Needs." Dr. Koop acknowledged that transition remained the *one* major issue for adolescents with chronic conditions that had *not* been adequately

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Manuscript accepted July 20, 1993.

Table 1. Estimated Proportion Surviving to Age 20 Years (%), United States¹

Disease	Estimated Proportion Surviving to Age 20 ^a (percentage)
Asthma (moderate and severe)	98
Congenital heart disease	71 ²
Diabetes mellitus	95
Cleft lip/palate	92
Spina bifida	50
Sickle cell anemia	90
Cystic fibrosis	60
Hemophilia	90
Acute lymphocytic leukemia	71 ³
End-stage renal disease	90 ⁴
Muscular dystrophy	25

^aEstimate refers to the survival expected of a birth cohort to age 20 years, given current treatments.

Figures based on:

¹Gortmaker SL, Sappenfield W. Chronic childhood disorders: Prevalence and impact, *Pediatric Clinics of North America*, 1984; 31:3-18 with revisions as noted.

²Moller J, Anderson R, (personal communication)

³Birth through 14 years of age. *Cancer Statistical Review*, National Cancer Institute, May 1989, NIH publication no. 89-2789.

⁴Actuarial 2-year survival data for patients ages 10-19 years with end-stage renal disease begun on treatment transplant or dialysis). US Renal Data System, *USRDS 1989 Annual Report*, NIH, National Institute of Diabetes and Digestive and Kidney Diseases, Bethesda, MD, 1989.

addressed by the health-care system, representing a significant barrier to adolescents and young adults as they attempted to obtain developmentally appropriate medical care and to function independently (3). The following year, the Society for Adolescent Medicine (SAM), the National Center for Youth with Disabilities (NCYD), and the Maternal and Child Health Bureau (MCHB) sponsored a third small invitational working meeting on transition: "Youth with Disabilities: A National Response."

This meeting brought together representatives of the major medical associations and organizations to discuss the key issues surrounding youth with disabilities and define priority areas for action. Activities, whether research, policy and service development, training, or national advocacy, were detailed for each organization. At the time, few models of health-transition programs existed. Over 2 years later, there has been little progress in development of health transition programs.

According to the 1988 National Health Interview Survey (NHIS) on Child Health, as many as 8.6 million, or 31.5% of adolescents ages 10-17 years had one or more chronic conditions (4). Table 2 shows the estimated prevalence and rates for 16 specific conditions drawn from a larger age bracket popu-

lation. The prevalence estimates of this study do not account for severity. Accordingly, not all of the conditions categorized as chronic are likely to be severe in nature. In fact, most of the conditions probably had a relatively small impact on adolescent activity and functioning levels. Newacheck and his colleagues (4) estimated that about 84% of adolescents with chronic conditions had no long-term limitations in their activities as a result of their conditions. This tends to support other evidence that most of the 8.6 million young people with chronic conditions do not have significant functional limitations and may make the transition to adulthood with no more difficulty than their healthy peers (5). However, 1.4 million—or 16%—of adolescents with chronic conditions, experienced limitations in their activities (4). Because most of those conditions are consistent with survival to adulthood, the rates of chronic illness throughout the early adult years will grow. Thus, the future health status for this ever-increasing number of young people rests on a health-care foundation that must be medically excellent and psychosocially sound. A smooth transition should be a priority and the shared responsibility of pediatric and adult health-care providers.

Table 2. Prevalence and Rate per 1,000 Persons of Selected Chronic Conditions for Persons 10-24 Years of Age: United States, 1986-1988 (Based on Total U.S. Population 10-24 Year Olds: 53,654,000)

Chronic Condition	Prevalence 10-24 years old	Rate per 1,000 persons
Arthritis	633,000	11.8
Asthma	2,696,000	50.2
Cerebral palsy	65,000*	1.2*
Cleft palate	46,000*	0.9*
Congenital heart disease	144,000	2.7
Diabetes	218,000	4.1
Epilepsy	273,000	5.1
Hearing impairments	1,425,000	26.6
Liver diseases (including cirrhosis)	33,000*	0.6*
Malignancies—all sites	21,000*	0.4*
Mental retardation	698,000	13.0
Multiple sclerosis	9,000*	0.2*
Paralysis of extremities, complete or partial	97,000	1.8
Speech impairments	561,000	10.5
Spina bifida	11,000*	0.2*
Visual impairments	1,003,000	18.7

Source: Unpublished data from the National Health Interview Survey, National Center for Health Statistics. Compiled with the assistance of John Gary Colling, Division of Health Interview Statistics.

*Does not meet standards of statistical reliability.

The Need for Transitional Programs

There is consensus among adolescent health-care professionals that all young adults, when developmentally ready, should receive their health care in adult-oriented settings, and that adolescents with chronic conditions should be given the opportunity to transfer their care in a gradual and purposeful fashion (6). In practice, however, some pediatricians and pediatric subspecialists believe that young adult patients should be cared for by pediatricians indefinitely (7-9). The majority of health professionals, however, are either unsure of the issues or are only peripherally involved. Systemic inertia, fueled by insufficient information about transition options and outcomes, helps maintain an outdated status quo (10). As a result, most adolescents make their way into the adult health system in an unplanned, uncoordinated fashion.

Adolescence, independent of health status, is a process of transition. A chronic illness adds to its complexity and importance. Puberty, autonomy, personal identity, sexuality, education, and vocational choices all may be influenced by impaired physical or mental abilities, pain, medical setbacks, forced dependence, and perceived prognosis. Young people, especially those with severe chronic illness, need multidisciplinary care and guidance from professionals who understand both the medical and psychosocial aspects of their conditions.

All individuals, whether receiving primary preventive care or tertiary care, deserve services that are appropriate for their age and developmental stage. The expectation that adolescents are working toward adult-oriented care enhances their sense of responsibility and personal control. It sends a message that they will survive; that this care is more than a temporary issue. It gradually shifts the decision-making from the parent to the adolescent-parent unit, and finally to the young adult. Health providers for children tend to be more protective, parent-oriented, and prescriptive compared to health-care providers for adults. The pediatric model that focuses on the parent may avoid critical adolescent issues such as sexual and reproductive health care, substance abuse, risk behaviors, vocational counseling, and independent living. Prolonged child-centered care may send the incorrect message that these issues are unimportant given the severity or poor prognosis of the underlying condition. It also may unwittingly emphasize the "difference" that young people with chronic conditions may feel when they receive their health

care in a setting from which their peers have graduated (11-13). The greatest gift may be a "letting go" in an environment that is supportive and in a process that is planned and thoughtful.

Current Status of Transition Research

There are few data evaluating the efficacy of transitional programs. No controlled studies of transition models exist and the criteria for success are often unclear. The discussion about transition often rests on the difficulty of obtaining appropriate, knowledgeable health care and anecdotal reports of teenagers and parents regarding other transition difficulties (14).

Choosing criteria for successful transition plans is complicated by chronic and, at times, fatal health conditions. "The primary goal of health care for these individuals is to maximize function in everyday life and to achieve the highest level of well-being" (15,16). Assessing success in transition must take into account disease-specific measures, functional status, and sense of well-being. Adequate standard measures exist (15,17,18); however, they have not been used in any study of transitional programs. Rather, investigators have relied on the rate of completion of referral (surely an important intermediate variable) (12), solely on disease-specific measures (19) or estimates of patient and provider satisfaction (20).

One report (12) indicated that adolescents with rheumatologic diseases were more likely to follow through with referral to adult health providers following the implementation of a transition clinic. This study was limited by its use of historical controls only. Another study from Finland (19) examined glycemic control of adolescents with insulin-dependent diabetes mellitus before and 1 year after transfer from a pediatric to adult clinic. Glycemic control was significantly better 1 year after the transfer. There was no control group in this study; therefore, it is impossible to determine if these findings were solely a function of maturation (21). Moreover, support was not provided for the authors' claim that duration of disease and gender influenced the impact of transfer.

Schidlow and Fiel (13) reported their experiences with a formal program to help adolescents with cystic fibrosis move into the adult health system. Although no data about outcome are available, the authors reported that it was impossible to predict who would be satisfied with movement to the adult clinic.

There is a clear need for research that evaluates the efficacy of different models of transition across a variety of chronic conditions. This research should follow patients for sufficient time (3–5 years) to account for the variation in natural history among the conditions (e.g., end-stage renal disease, chronic lung disease, congenital heart disease, metabolic problems, and those with severe handicaps who are technology dependent). Outcome measures should include rate of completion of referrals, functional outcome, sense of well-being, and patient satisfaction.

Current Foundation of Transition: More Assumptions, Key Elements, and Research Questions Than Scientific Data

Although a small number of model programs provide transitional care, there are no data on the efficacy of these programs in promoting the health and well-being of adolescents and young adults. In fact, even the number of such transition programs is not known, and there has been no systematic effort to identify and analyze them. While many assumptions and hypotheses are made about the benefits and impact of programmed transition on young people's health, the reality is that none of the existing transition programs have been designed for or funded at levels allowing for controlled studies of outcome. Although the Maternal and Child Health Bureau has funded several transition programs (22), the failure to collect systematic data leaves us with only anecdotal evidence based on observations of those various transition programs. Assumptions, key elements, or research questions are the building blocks of research and model program design. If the debate over transition is to be a productive one, those assumptions, elements, and research questions need to be discussed and open to critical appraisal.

Assumptions

The assumptions most often made about the processes and outcomes of transition include the following:

1. Transition is a multifaceted, active process that attends to the medical, psychosocial, and educational/vocational needs of adolescents as they move from the child-focused to the adult-focused health-care system. Health transition facilitates transition in other areas of life as well (e.g., work, community, and school). It implies an increase in independent behavior and personal autonomy

but need not entail a change in health providers. For example, children who see family practitioners may remain in this setting throughout adulthood. In other words, transition is *more* than, and sometimes distinct from, simple referral to a physician caring for adults.

2. Transition proceeds at different rates for different individuals and families. Most developmental transitions create anxiety. The anxiety is beneficial when it facilitates growth (e.g., trying new skills to increase self-sufficiency). Anxiety may be detrimental if it inhibits growth (e.g., parental or provider fear that keeps the young adult forever tied to the child health-care system). Therefore, health providers need to work with adolescents and their families. They must help young people negotiate the transition and must support both maturing patients and concerned parents in the process. Timing of the transition will depend on developmental readiness, complexity of the health problems, characteristics of the adolescent and family, and the availability of skilled adult health providers.
3. Transition is more complex and generally more difficult for those with more-severe functional limitations or more-complicated medical conditions. These individuals will require a formal plan developed over a longer period of time (6,14,20). Adolescents with multiple limitations (e.g., myelodysplasia), will require help with transfer to multiple specialists, including a primary physician to coordinate care. They may need special counseling about school, jobs, living options, transportation, and health insurance.

Key Elements

Analysts and observers of current programs that provide "transitional" services suggest at least four key elements that may make some programs more "successful" than others. Again, however, because there are no "hard" data evaluating the efficacy of transition programs, these key elements are more assumption than outcome-based research markers for success. Those elements are as follows:

- professional and environmental support,
- decision-making and consent,
- family support, and
- professional sensitivity to the psychosocial issues of disability.

Professional and Environmental Support. Inherent in the concept of "transition" is the philosophy that

children are expected to mature as they become adults. Maturation requires support systems that accommodate and facilitate biological, social, and psychological growth. The environmental and professional support required by children is quite different from that of the middle adolescent who is developing new skills in autonomy and independence. In turn, the young adult has needs for establishing self-sufficiency far beyond those of the late adolescent. The "ideal" transition plan takes each of these axes into account. Because the needs, particularly of those with more-severe problems, are often complex, interdisciplinary care is often necessary. This permits a variety of professional and community support systems to provide care in an effective, organized way.

Each professional must accept and promote the transition process and affirm that movement from the child-focused health system is both desirable and necessary. This may require introspection on the part of the pediatrician who has provided care for the entire life of the adolescent. It may require a comprehensive developmental approach from the adult medicine practitioner, rather than the more-traditional systems or disease-specific approach. The model of geriatric care with its attention to psychosocial and biological needs is familiar to physicians in internal and family medicine and in many ways is analogous to caring for this age group. Adequate financial support is also essential.

Decision Making and Consent. Adolescents must be permitted, and at times encouraged, to take an increasingly more active role in their health care. As they become cognitively and socially more mature, they develop new capacities that enable them to make treatment decisions. Health providers and parents must support this process and, especially for more-passive or cognitively impaired individuals, must help them develop developmentally appropriate, decision-making skills.

Family Support. Healthy families constantly adjust the type of support they provide to their growing children. Parents and adolescents continually negotiate and renegotiate the boundaries between supervision, autonomy, and independence. Adolescents require parental support to become independent both in social and health-related behaviors. Parents often require support of health providers to negotiate the boundaries. Together they must balance the need to supervise for the sake of safety with the adolescent's need to "act as an adult." For most healthy

and impaired youth, this process, though at times exasperating, is a natural one. For the more severely impaired young person, however, parents may for the best of reasons overprotect and thus hinder the attainment of maximal self-sufficiency and personal growth. Parental anxiety may become intense as the adolescent moves into the adult world with a changing health-care system and independent living arrangements. The anxiety may interfere with or impede these necessary transitions. The transition program or plan must assist families adapt their support to maximize growth of the young person.

Professional Sensitivity to the Psychosocial Issues of Disability. As increasing numbers of children with previously fatal conditions become adults, the need for health professionals skilled in their care increases. Physicians, nurses, and other health professionals trained in the traditional adult specialties are generally unfamiliar with *pediatric* health conditions. Moreover, they may not appreciate the additional needs of disabled youth who are confronting the adult health system for the first time. If child-focused care (primarily pediatric) tends to suggest more dependency, adult-focused care tends to demand independence. The transitional plan monitors this balance assuring that the expectations of both pediatric and adult providers are realistic.

Movement to adult-focused health care involves shared responsibility between pediatric and adult health professionals to assure that care is continuous. It also involves shared learning. Pediatricians may become anxious with the appearance of adult sequelae of childhood illness in their adolescent patients; adult specialists may be equally uncomfortable because they are unfamiliar with these diseases. Reciprocal professional education can be a rewarding process. Training in transitional care, however, has been uniformly lacking in the education of medical students and residents in primary care and medical specialties.

Research Questions

The following represent research questions that require formal study within model transitional programs:

- Which patient characteristics (medical, social, psychological) identify those who need a transitional program?
- Which types of programs are most effective?
- Do different models of transitional care produce equivalent medical and psychosocial outcomes?

- Do adolescents who move from child-centered to adult health care via a transition program have fewer medical complications than those without such a program?
- Do adolescents who move from child-centered to adult health care via a transition program do better emotionally and socially than those without such a program?
- Are adolescents and their families who move from child-centered to adult health care via a transition program more satisfied with their care than those who move without such a program?
- Are young adults who remain in child-centered care less optimistic about their futures than young adults (with similar disease severity) who move to adult health care?
- Are routine adult health screening and counseling less likely to occur for patients who remain in child-centered care than for those who move to adult health care?
- What are the most appropriate outcome measures for evaluative research?

Conclusions/Summary Position

Transition to adult health care is a component of high-quality health care to adolescents with chronic conditions and, as such, should be promoted. The Society for Adolescent Medicine acknowledges that scientific data on the impact of transition on the adolescent's health status and functional level do not exist. It is, however, critically important that we promote discussion of transition issues, development of transition programs, and thoughtful evaluation of such programs. If we are to help adolescents with chronic conditions develop to their fullest capacity, we must understand what works and why. To accomplish that, we must move to the next level of activity. It is, therefore, the official position of the Society for Adolescent Medicine to recommend the following:

- increased federal funding of model transition programs designed to meet adolescent developmental needs;
- targeting existing federal research funding by prioritizing requests for proposals (RFPs) for transition-related, adolescent-focused projects;
- sustained federal funding for the development and comprehensive evaluation of several different models of transition across a spectrum of chronic conditions;

- collaborative efforts by the Society for Adolescent Medicine and other professional medical organizations (American Medical Association, American Academy of Pediatrics, American College of Physicians, American Academy of Family Physicians) and industries (e.g., health insurance industry) with respect to transition issues; and
- the inclusion of transition issues in the professional education of medical students, residents in pediatrics, internal medicine, family medicine, and rehabilitation medicine, nurses and nurse practitioners, and other health-care providers, stressing a shared responsibility in the treatment of adolescents and young adults.

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