

Health Care Transition: Destinations Unknown

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ABSTRACT. The movement of young adults with special health care needs from pediatric-oriented care to adult-oriented care has been a growing concern in the health care literature over the past 20 years. This article reviews the development and evaluation of health care transition policy over that period of time. These health care transition policies are discussed in light of the preliminary results from a qualitative study of the experience of health care transition. This article concludes with suggestions regarding future policy development and research efforts around health care transition. *Pediatrics* 2002;110:1307–1314; *adolescence, transition, health care policy.*

ABBREVIATIONS. MCHB, Maternal and Child Health Bureau; HRTW, Healthy and Ready to Work; CAS, complex adaptive system.

INTRODUCTION

Over the last year, we (John Reiss and Robert Gibson) have held a series of focus groups with a broad range of youth and young adults, family members, and health care providers who have first-hand experience with caring for individuals with special health care needs who are making the move from child-oriented to adult-oriented care, that is, health care transition. Through our focus groups and surveys, we anticipated finding that there were a relatively small number of truly significant issues in health care transition; that there were many examples of successful transition programs; that transition programs had developed promising policies and practices that could be adopted by other organizations interested in improving their transition services; that appropriate funding and financial incentives were key to supporting implementation of promising practices and model policies; and that by disseminating information about promising practices and model policies (and given appropriate funding and financial incentives), programs and providers would more effectively support youth and their families in their planned movement from pediatric to adult health care systems. Our initial results, however, indicate that health care transition is a much

more complex and dynamic phenomenon than expected and that, for most youth, health care transition is a journey that does not have a clear destination. On the basis of our findings, we have identified 3 major challenges in health care transition policy and program development.

First is the need to continue long-term work at the systems level to design, develop, finance, assess, and refine a health care continuum that serves children, youth, and young adults with special health care needs. Over the last 3 decades, great progress has been made at the “child and family” end of the continuum in developing family-centered, community-based, coordinated, culturally competent systems of services. The challenge now is to do comparable development at the adult-oriented end of the continuum so that health care services and supports for young adults are as desirable as the child-oriented components of the continuum. Additionally, transitioning must be integral to this continuum so that movement toward adult-oriented systems is the normal, expected, and desired outcome of pediatric care. Development of such services and supports and the associated changes in expectations and norms is a long-term, ongoing undertaking that will most likely take decades.

Second and at least equally important is the need to work now at the personal health care level to inform and train health care providers, family members, and youth about transition as a necessary and important aspect of quality health care and to educate and motivate these key stakeholders to become active participants in the transition process at the individual and practice levels. Health care providers need to make health care transition a priority now and integrate health care transition into all aspects of pediatric, adolescent, and young adult health care practice. As will be seen, it represents a developmental framework for delivery and planning health care services.

Third is the need to fully acknowledge and appreciate the multiplicity of interacting factors that impact health care transition and to use models for representing health care transition that are in keeping with the complex and dynamic nature of this phenomenon. By using such models, we will be better able to articulate health care transition policies and real-world approaches that can be used by providers and payers to promote and sustain needed changes at the federal, state, community, and individual practice levels in the organization, financing, and delivery of health care for young adults with special health care needs.

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This article includes a brief review of health care transition program and policy development followed by a description of the current working model of health care transition, an alternative model based on our research findings, and recommendations for future health care transition policy and program development.

WHERE WE HAVE BEEN: A BRIEF REVIEW OF HEALTH CARE TRANSITION

Before the medical advances of the 1970s and 1980s, the transition to adult health care for most children with complex medical conditions was a moot issue. Few of these children survived into adulthood. In 1973, the average age of survival for a child with cystic fibrosis was 7 years; today in industrialized nations, half survive to 31 years of age,^{1,2} and in the United States about one half of all individuals with cystic fibrosis are 21 years or older. Similarly, in the 1970s less than one third of youth with spina bifida reached 20 years of age. Today, more than 80% of young people with this diagnosis reach adulthood.

Currently, the number of young people with a chronic health condition or disability is significant. More than 90% of children born today with a chronic or disabling health condition are expected to live more than 20 years.³ Newacheck and Taylor^{4(p367)} reported "20% of US children experienced a mild chronic condition, 9% experienced chronic conditions of moderate severity and only 2% of children experienced severe chronic conditions in 1988." Using the Maternal and Child Health Bureau (MCHB)'s definition⁵ of children with special health care needs, published data report a prevalence of about 15%.⁶ On the basis of this rate, we estimate that every year, more than 500 000 children with special health care needs turn 18 years of age.

Although these overall numbers are large, the number of youth with a given health condition in a given geographic region who turn 18 years of age is relatively small, and no data are currently available regarding the proportion of young adults with childhood-onset chronic conditions who currently receive adult-oriented health care.

During the 1980s, there was a growing awareness in the health care community that there was a need to more appropriately accommodate the health care needs of the ever-increasing number of youth with special health needs that were living into adulthood. In response to this, US Surgeon General C. Everett Koop, MD, convened an invitational conference in 1989 titled "Growing Up and Getting Medical Care: Youth With Special Health Care Needs."⁷ This conference developed an action agenda that focused on the needs of young adults, family members, and health care providers and addressed the key issues of provision of services, financing of care, training of staff, and needed areas of research.

During the 1990s, there was progress in identifying the factors that impact transitioning, in developing transition demonstration projects, in describing key transition program components, and in identifying needed changes in professional knowledge,

skills, and attitudes. Position papers and committee reports on transitioning were developed and promulgated by the Society for Adolescent Medicine,⁸ the Cystic Fibrosis Foundation,^{2,9} the Transition Committee of the Federal Supplemental Security Income/Children With Special Health Care Needs Workgroup,¹⁰ the American Academy of Pediatrics,^{11,12} the American Medical Association,¹³ and the MCHB.^{7,14}

As a whole, these policy statements acknowledge the importance of a planned and orderly transition to adult systems and encourage physicians and other professionals to inform, educate, assist, and support youth so that they can adapt positively to an adult-focused system of health care.

A number of nationally recognized authorities^{8,15-19} in adolescent health and disability also published articles that include their expert opinions regarding the guiding principles of transition services and the design, development, and operational characteristics of effective transition programs.

In addition, a number of reports on the operations of transitioning programs and practices have been published, many of which served a specific chronic condition or disability.²⁰⁻²⁵ Programs and practices related to transition have also been reported within the context of professional disciplines.^{8,11,19,26-29}

A rich body of information on transitioning to work, independence, and adult care has been developed through MCHB's "Healthy and Ready to Work" (HRTW) Initiative. Projects funded through this initiative participate in the HRTW Network, which promotes information sharing and project-to-project consultation. Although some information developed by the HRTW projects has appeared in the professional literature, much more information is documented in special reports, progress reports, and other project materials and are available online (<http://www.mchbhrtw.org>).³⁰

In support of MCHB's HRTW Initiative, the Institute for Child Health Policy hosted a follow-up meeting to the Surgeon General's 1989 conference. This meeting, held in 1999 and titled "Transition Revolution: You Can Make It Happen in Health Care,"³¹ brought together a group of 50 health policy administrators, analysts, and leaders as well as physicians, nurses, teachers, family representatives, advocates, and adolescents with disabilities. In reviewing the priorities and actions that were developed at the original Surgeon General's Conference, participants generally agreed that the 1989 agenda focused on the right issues and set out an appropriate plan of action. It was acknowledged however, that a variety of factors had impeded effective sustained action and that most activities in the 1989 document had yet to be implemented.

The 1999 conference participants developed a wish list of activities that were needed to continue to move the transition agenda forward. These activities were organized into 4 major issues:

1. access: from pediatric to adult health care;
2. partnerships for successful outcomes: family, youth, and professional;

3. coordination: sustaining quality, compassionate health care; and
4. financing: bridging the funding streams of health care.

Recommendations for action were generally at the systems level and included:

- ensuring that each individual has a primary care physician who provides a coordinated, affordable, and streamlined comprehensive care program;
- creating a uniform benefit package for all individuals with chronic illnesses and disabilities across states;
- developing appropriate quality measures and practice guidelines;
- increasing public awareness about the seriousness of transition issues;
- creating a stronger, consumer- and youth-driven interagency collaboration around performance evaluation for transition issues;
- educating policy makers so they know there are health care systems in place that do not work for certain segments of the population; and
- mandating linkages in federal laws for different systems so the issue of transition becomes a focal point around which to work.

The outcomes of this conference served as the basis for the health care transition component of the MCHB's 10-year agenda.³² This updated agenda sets as its overarching goal to ensure that "all youth with special health care needs will receive the services necessary to make transitions to all aspects of adult life, including adult health care, work, and independence" by carrying out the following 4 action steps: ensure that youth with special health care needs participate as decision makers and as partners; ensure that all youth with special health care needs have medical homes responsive to their needs; use Title V to facilitate the development of transition systems for children, youth, and young adults with special health care needs and their families; and provide youth with special health care needs with accessible and affordable health insurance coverage.

These recommendations for transition were incorporated into MCHB's draft 10-year plan titled "Achieving Success for All Children and Youth with Special Health Care Needs",¹⁴ which includes the following 5 additional goals for the nation:

- All children with special health care needs will receive coordinated ongoing comprehensive care within a medical home.
- All families of children with special health care needs will have adequate private and/or public insurance to pay for the services they need.
- All children will be screened early and continuously for special health care needs.
- Families of children with special health care needs will partner in decision-making at all levels and will be satisfied with the services they receive.
- Community-based service systems will be organized so families can use them easily.

Almost all of this policy work has been conducted by child-oriented professionals, organizations, and family leaders, and this work focuses primarily on the process of preparing for the transition to adult systems. Little work has been done by those on the receiving end of transition to prepare adult-oriented providers, programs, and facilities for the young adults who leave pediatric care.

WHERE WE THOUGHT WE WERE GOING

For more than a decade, health care professionals, families, youth, policy makers, and others have been working to improve the organization, financing, and delivery of health care for individuals with special health care needs who are moving from adolescence to young adulthood. However, despite all of these efforts, relatively little progress has been made in putting good ideas into general practice and institutionalizing approaches that would help ensure that youth with disabilities have access to the services and supports needed as adults.

The working model of health care transition that many of us use currently, implicitly or explicitly, is based on the definition that was articulated in the position paper of the Society for Adolescent Medicine, which states that 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 system."⁸

This position paper goes on to note that the assumptions most often made about the process and outcomes of transition include the following:

1. Transition is a multifaceted, active process that attends to the medical, psychosocial, and educational or vocational needs of adolescents as they move from the child-focused to the adult-focused health-care system. Health care transition facilitates transition in other areas of life as well (eg, work, community, and school). It implies an increase in independent behavior and personal autonomy but need not entail a change in health providers. . . children who see family practitioners may remain in this setting throughout adulthood.
2. Transition proceeds at different rates for different individuals and families. Most developmental transitions create anxiety. . . 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.

This position paper also identified 4 key elements that "may make some (transition) programs more 'successful' than others." These elements are:

1. *Professional and Environmental Support.* Maturation (and transition) requires support systems that accommodate and facilitate biological, social, and psychologic growth. . . each professional must ac-

cept and promote the transition process and affirm that movement from the child-focused health care system is 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.

2. *Decision-Making and Consent.* Adolescents must be permitted and at times encouraged to take an increasingly more active role in their health care.
3. *Family Support.* Adolescents require parental support to become independent 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.
4. *Professional Sensitivity to the Psychosocial Issues of Disability.* Movement to adult-focused health care involves shared responsibility between pediatric and adult health professionals to ensure 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 transition care, however, has been uniformly lacking in the education of medical students and residents in primary care and medical specialties.^{8(p574)}

The model of health care transition articulated in the Society for Adolescent Medicine position paper has a number of significant characteristics and implications for policy, program development, and planned change. In this model, health care transition is linear, with movement in one direction, from child-centered to adult-oriented health care. Child-centered and adult-oriented health care are viewed as separate systems of care. Purposeful planning takes place primarily within child-centered health care; adult-health care systems are the passive recipients of young adults as they move out of child-centered (pediatric) systems. Appropriate and comparable adult-oriented health care systems are assumed to exist. All adolescents and young adults should be moved out of child-centered health care and into adult-oriented systems when such a transition is developmentally appropriate. Relatively few factors are recognized as impeding transition. These include parental anxiety, reluctance of pediatric providers to "let go," and limited experience of adult providers with childhood-onset conditions.

WHERE WE ARE

In contrast to the relatively linear process represented in the Society for Adolescent Medicine position paper, individuals who participated in our focus groups described health care transition as a complex and dynamic process that is affected by a large number of forces and factors. Some of these forces pro-

mote health care transition, and others impede the process of moving from pediatric to adult systems in a planned and purposeful way.

Focus group participants spoke about the intensity of the relationships in pediatric health care, the importance of trust, and the multiplicity of ongoing challenges that families with children with special health care needs must face. They also spoke about the difficulty of terminating the lifelong relationships that have developed with pediatric providers, the emotional and intellectual challenges of building working relationships in new health care settings, and the fears that adult professionals did not know as much about or provide as high a quality of care as had been provided by their pediatric providers. They also spoke about the impact of changes in health insurance coverage and the age limits set by agencies, such as state Title V Children With Special Health Care Needs Programs; facilities, like children's hospitals; and providers, including pediatric primary care providers and specialists.

Participants also indicated that the adult-oriented health care services toward which youth are to transition (in the ideal health care transition process) typically are not readily available. Even in communities in which health care transition was said to be a priority, there was often no identifiable, appropriate adult-oriented health system to which youth with chronic health conditions could move. In addition, it was reported that when young adults did receive care from adult providers and programs, this care was often deemed unsuitable or undesirable by youth, families, and pediatric providers. We also heard repeatedly that, in the absence of a viable health care transition destination, many young adults, family members, and providers were working creatively to fashion, "a patchwork quilt of health care services" from all available sources.

From our preliminary analysis of focus group data, we have organized the forces that promote and impede the movement from child-centered to adult systems under the following 3 factors: service needs, structural issues, and personal preferences and interpersonal dynamics.

We do not propose that these are the only 3 forces working for and against the process of transition; rather, these factors are presented as the ones identified by many of our study participants as having a significant impact.

Service needs refer to the availability or absence of treatment services and the degree to which a service satisfies the young adult, family member, and health care provider. Service needs that promote health care transition include the young adult's desire for developmentally appropriate treatment services (personal, sexual, social) that address the changing and maturing needs of young adults, including services that address his or her reproductive issues and concerns. Additionally, there is often a lack of adult-focused primary and preventive services in the typical pediatric setting, such as breast and testicular cancer examinations, provision of birth control, or pelvic examinations. Further increasing the need for transferring to adult health care providers is the prefer-

ence of many pediatricians not to address issues such as pregnancy, involvement in the criminal justice system, or substance abuse. Finally, the child health care system is under continuous financial pressure to make room for new and younger children with special health care needs.

On the other hand, there are several factors that impede the health care transition process. First is the lack of availability of needed treatment services in the adult health care system. This ranges from adult specialists to specific interventions. Providers often reported that there was no place to refer young adults ready for transition; families and youth reported not being able to find providers who were willing to treat their special health care needs. Second, treatment services, when available, are often not viewed as comparable to pediatric care. Providers, families, and youths reported that certain important life-sustaining treatments are only available in a pediatric treatment setting. Finally, young people with special health care needs and their parents reported that adult providers often do not have a working knowledge of or extensive experience treating the disability or special health care need. Providers, families, and youths indicated that on the basis of their personal experiences, the medical knowledge and experience necessary to manage childhood-onset chronic diseases is often not evident from adult physicians or facilities. This deficit is often expressed through stories about care that was less than adequate or had jeopardized a young adult's health.

Structural issues refer to institutionalized medical practices, such as education and training, inter-agency cooperation, insurance coverage, and institutional policies. As with service issues, those who participated in the focus groups identified a range of structured issues that promoted and impeded health care transition. Structural factors that were promoting included the following:

1. Policies that denied or limited service to young adults (eg, provisions of a health insurance policy that precluded reimbursement for certain services provided to individuals over a particular age; age limits for Title V Programs for Children With Special Health Care Needs; dependent health insurance status; age-related changes in Medicaid financial eligibility and benefits protections; and policies of children's hospitals, clinics, and medical practices regarding the upper age limit of patients);
2. Licensing and practice limitations of practitioners (eg, anesthesiologists' refusal to give anesthesia to adults being cared for in children's hospitals or the practice limitation of pediatric nurse practitioners to individuals younger than 25 years); and
3. Mission of facilities and charities (eg, the mission of a children's hospital is stated as serving children [and not young adults] with a childhood-onset condition or charitable foundations funding care for individuals younger than 21 years).

Structural issues that tend to impede transition include the absence of referral networks between

pediatric providers and treatment settings and adult providers and settings. Additionally, differences between pediatric and adult systems in regard to style or approach to treatment and availability of ancillary supports and services was noted as a barrier. Providers, families, and youths expressed dissatisfaction with the lack of multiple services and professional expertise in a single setting, needing to see different providers for care of different body systems, longer time between follow-up visits, and lack of outreach by adult provider systems. Third, young adults and their families said that they are not informed about or prepared to accommodate to the standard practices, policies, and procedures of the adult systems. Expectations of young adults and families are not reconciled with these differences in the adult care model. Fourth, medical specialties are age segregated with the consequence that pediatric- and adult-trained professionals in the same subspecialty have limited shared training, communication, and expertise. Further complicating health care transition is the linkage of insurance to employment. Many youth and young adults lack the health insurance they need to get care from the adult health care system, because family health insurance coverage typically ends for dependent children between 18 and 23 years of age. The societal norm for young adults is that insurance coverage is available through employers. Many health insurance safety net programs that are available to children (eg, state Title V Children With Special Health Care Needs Programs, Early and Periodic Screening, Diagnosis, and Treatment Programs, and the State Children's Health Insurance Program) are not available to young adults. In addition, health insurance benefits (amount, duration, scope, and provider of service) change because of age, but needs remain the same. Finally, adult systems are frequently unable to provide care, which leads to the young adult being referred back to the pediatric system.

Personal preferences and interpersonal dynamics refer to an individual's likes and dislikes, attitudes, and values and to the psychologic and emotional aspects of relationships between and among youth, families, and professionals. Again, the focus groups identified a number of preferences and dynamics that impact health care transition. Personal preferences and interpersonal dynamics that tend to promote transition include desire on the part of the young adult to be seen and treated as an adult (eg, hospital visiting hours, television privileges). As stated by one respondent, "I don't want to be on a hospital floor with crying infants and children in the next bed." Second, youth often report a desire for privacy and confidentiality that is not available on a pediatric unit. Finally, when they are able to receive care from their pediatric health care provider in the adult health care setting, young people and parents report that the transition process is easier.

Personal preferences and interpersonal dynamics that tend to impede transition include adult providers' expressed lack of respect for medical knowledge and expertise of young adult patients and family members regarding their chronic illness. Family

members and young adults reported that they are often not respected as knowledgeable members of the treatment team by professionals in the adult-oriented health system. Pediatric providers' distrust of adult medical providers' knowledge and ability to appropriately manage childhood-onset chronic health conditions further impede health care transition. Providers, families and youths indicated that they experienced or knew about situations in which a young adult did not receive care from the adult health care system that was comparable in quality to that provided in the pediatric system, leading to exacerbations of the chronic condition, deterioration of health status, or death. Difficulty of pediatric providers, young adults, and families to terminate clinical relationships in a therapeutically effective manner also limits health care transition.

From our analysis of focus group data, we have also concluded that the forces that impede and facilitate health care transition result in 4 predominating models of health care delivery for young adults with special health care needs: 1) continuing to receive care from pediatric providers, facilities, and programs; 2) receiving health care from pediatric and adult providers, facilities, and programs (blending or braiding of pediatric and adult services); 3) receiving all care from adult providers, facilities, and programs; and 4) dropping out—having no source of regular health care.

It is important to note, however, that there are significant variations in the organization, financing, and delivery of care within each of these outcome categories. Within 3 of the 4 categories, there are a range of adaptations that young adults, families, and providers have made to access care that meets and satisfies the expectations of all involved. Our respondents reported following adaptations:

- Providers, families, and young adults ignored facility and program policies regarding age and continued to provide and/or seek treatment from pediatric treatment centers and professionals. There was often full agreement from young adults, families, and providers that they were happy with this arrangement and would continue until forced to change.
- Pediatric facilities and programs established (or are planning to establish) adult-oriented clinical service generally using the pediatric staff, support models, and locations.
- Pediatric providers have modified their practices to accommodate adult clients.
- Pediatric providers have broadened their knowledge and skill base to follow pediatric patients into adulthood.
- Providers, families, and youths have developed informal, patient-specific patchwork quilts of care. For example, young adults go to a general internist or family physicians for primary and acute care and continue to receive the care related to their chronic health condition from pediatric specialists through pediatric facilities and programs, but there is little or no communication between the pediatric and adult providers.

- Providers have developed formal programs or informal arrangements that support shared management. For example, adult-trained specialists and pediatric-trained specialists work as a team, or a general internist provides primary care and addresses acute care needs and uses pediatric-trained specialists for consultation.

As more and more youths with chronic conditions reach adulthood, there will be even more pressure on the pediatric and adult health care systems to continue to provide the level and quality of care that the pediatric system has provided during that individual's life. There will also be pressure on pediatric systems to continue to serve youth with chronic conditions into adulthood, in response to the continuing absence and availability of quality adult-oriented care. There will also be more consumer- and provider-developed patchwork quilts of medical care.

Although health care transition was an elusive goal for many individuals, the focus groups did reveal a number of factors associated with successful health care transition, including the following:

1. *The family, young adult, and provider have a future orientation.* This involves an awareness of the future demands and expectations of living as an independent young adult as well as specific goals and dreams.
2. *Transition is started early.* Many respondents talk about this occurring at or near the time of diagnosis or when children are very young. It was generally agreed that it is too late to start the transition process during adolescence.
3. *Family members and health care providers foster personal and medical independence.* This involves being responsible for as much self-care as possible as early as possible.
4. *Planning occurs for the future* regarding insurance coverage, providers, equipment, and skills necessary to navigate the adult health care system.
5. The young adult verbalizes the *desire to function in the adult medical world*, and this outweighs the benefits of pediatric practice models.
6. *Reimbursement for services is not interrupted*, and level of services provided in the adult health care system remain comparable to pediatric services.
7. Pediatric providers continue to provide care into adulthood but change the location of service delivery to adult clinics or practice.
8. Individuals are able to continue to receive services from the same health care system. Services that are community- or institutionally based, such as a general hospital, are better able to provide a continuity of services than facilities that served only children.

WHERE WE ARE GOING

Changes in both the pediatric and adult health care systems are necessary for health care transition to be a successful process. However, these system changes are long-term and will require many years to complete. In the meantime the respondents in our study were explicit in their statements and behavior that

they cannot wait or postpone health care transition in anticipation of possible or future systems changes. Their health care transition needs are current and present today.

What can be done, now, to make health care transition a reality, while acknowledging the intensity of interpersonal relationships in medical settings, the complex nature of health care transition, and the changing dynamics of the health care environment, within which the process of transition takes place?

First, we can learn from our psychotherapist colleagues about the process of terminating long-term, emotionally laden relationships. Interpersonal relationships were identified as a very important part of the health care experience by all of our respondents (professionals, youth, and families). However, results of our research suggest that little time and attention are given by professionals to managing the termination process. According to focus group participants, those in pediatrics do an excellent job of building close working relationships with their patients and families and providing emotional support as well as medical care. However, most of the health care professionals with whom we spoke indicated that they had no training in how to appropriately terminate these caring relationships and no framework for how to “say good-bye.” Therefore, little time or attention was paid to working through the feelings of loss, anger, abandonment, and joy that are a natural part of major changes in a valued relationship. This failure to promote “closure” in pediatrics makes it even more difficult for young adults to establish satisfactory relationships with new providers in the adult system. Therefore, it is important for health care professionals to more closely attend to the ways they build, change, and end the working relationships they have with the children and families they care for.

Second, we can learn from recent developments in complexity science. In complexity science, human organizations (eg, children’s hospitals, state Title V agencies, or the health care system as a whole) are seen as a complex adaptive systems (CAS). Complexity science describes a CAS as being composed of “agents” that interact across the multiple organizational levels of the CAS. These agents are diverse in terms of their form and their capability. No single agent is in control of a CAS, and the long-term future of such a systems is unknowable. However, the interaction among agents at multiple levels leads to the emergence of more complex behavior at higher levels of the organization and to adaptations to change that are unpredictable yet purposeful. In addition, every agent in a CAS can have an impact on the system as a whole, which is sometimes (and particularly under conditions of instability) out of proportion to what seems logical from a linear cause-and-effect perspective.

From what we have seen, health care transition is a complex, dynamic phenomenon that involves interaction among diverse individuals and organizations. We have also seen that this interaction has led to a variety of different, unanticipated approaches to adapting to the changes inherent in moving from

pediatric to adult systems. Following are some of the guiding principles for having a positive impact on such systems:

- Give up the idea that we can design the future.
- Create connections or the potential for them.
- Create space for discovery and let information flow.
- Emphasize the value of diverse points of view.
- Value stories about past, present, and future.
- Increase the number of goals and pursue multiple generic strategies.
- Increase the number of external contacts.
- Teach people what other people are doing.
- Participate actively.
- Take on ambiguous challenges, for they inspire innovative responses.

RECOMMENDATIONS TO FACILITATE TRANSITION

The following recommendations are based on the principles of complexity science, counseling theory, and the experiences of the respondents in our focus group study. These are designed to be practical suggestions and behaviors that can be incorporated into daily practice patterns and used to educate families and young people about the importance of preparing for health care transition.

1. Have an orientation that is future focused and flexible. Most children with chronic illnesses are surviving into adulthood. Discuss with family members early on what they want and expect the adult life of their child to look like. Although expectations will change over time, the discussion will facilitate thinking and discussions of health care transition.
2. Anticipate change and develop a flexible plan for the future. Clinics and children’s hospitals, insurance policies, and providers often have time and service limits. Programs often discontinue services after 18 years of age. When service continues after 18 years of age, the nature or level of service is often different from when provided to those younger than 18 years. The time to discover these future changes is when the provider and the family have many years to plan.
3. Foster personal and medical independence and creative problem solving. The child should become a responsible member of the treatment team as early as possible. Medical practices and participation in the health care process should be established as a habit when children are young. Children should be asked to participate in medical examinations as primary respondents and assume responsibility for treatments at home and at school.
4. Develop a transition plan. Anticipate future needs by developing personal life maps. Use plans as a means to document completed and anticipated transition activities; including the emotional work involved in saying good-bye.
5. Celebrate transitions as they occur with graduation ceremonies, certificates of completion, and other rites of passage.

Health care providers, facilities, and programs can also support health care transition by developing clear transition policies, guidelines, goals, and expectations that are accommodated to unique individual situations; including healthy young adults in health care transition program planning; promoting interaction between youth and those who have transitioned to adult systems; establishing formal and informal connections with adult providers and provider systems; helping families, young adults, and providers establish therapeutic, working relationships that are mutually satisfying; educating families and young adults about ways to interact with the adult health care systems; cultivating interactions and connections with adult-oriented health care providers, alerting them to the problem of health care transition, and soliciting suggestions for change; extending professional relationships across age-defined specialty practice areas; and creating written transition plans that are updated and modified as circumstances change.

By following these recommendations, health care providers, programs, and facilities can help ensure that youth and young adults are prepared to make necessary health care transitions and that policies and programs are in place that support individuals through the process of moving from child-centered to adult-oriented health care.

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REFERENCES

- Bronheim S. A background issue brief. In: Magrab P, Millar H, eds. *Surgeon General's Conference. Growing Up and Getting Medical Care: Youth With Special Health Care Needs*. Washington, DC: National Center for Networking Community Based Services, Georgetown University Child Development Center; 1989:5–10
- Cystic Fibrosis Foundation. Adult Focus Web site. Available at: <http://www.cff.org/adultfocus.htm>. Accessed February 21, 2002
- Gortmacher SL, Sappenfield W. Chronic childhood disorders: prevalence and impact. *Pediatr Clin North Am*. 1984;31:3–18
- Newacheck PW, Taylor WR. Childhood chronic illness: prevalence, severity, and impact. *Am J Public Health*. 1992;82:364–371
- McPherson MA, Arango P, Fox H, et al. A new definition of children with special health care needs. *Pediatrics*. 1998;102:137–140
- Newacheck PW, Strickland B, Shonkoff JP, et al. An epidemiologic profile of children with special health care needs. *Pediatrics*. 1998;102:117–123
- Magrab P, Millar H, eds. *Surgeon General's Conference. Growing Up and Getting Medical Care: Youth With Special Health Care Needs*. Washington, DC: National Center for Networking Community Based Services, Georgetown University Child Development Center; 1989
- Blum R, Garell D, Hodgman C, et al. Transition from child-centered to adult health-care: systems for adolescents with chronic conditions. *J Adolesc Health*. 1993;14:570–576
- Cystic Fibrosis Foundation. *Guidelines for the Implementation of Adult CF Programs*. Bethesda, MD: Cystic Fibrosis Foundation; 1998
- Institute for Child Health Policy. *Federal CSHCN/SSI Workgroup Minutes—December 2–3, 1993*; Baltimore, MD. Available at: <http://www.ichp.edu/ssi/materials/workgroup/893776908.html>. Accessed February 21, 2002
- American Academy of Pediatrics, Committee on Children With Disabilities and Committee on Adolescence. Transition of care provided for adolescents with special health care needs. *Pediatrics*. 1996;98:1203–1206
- American Academy of Pediatrics, Committee on Children With Disabilities. General principals in the care of children and adolescents with genetic disorders and other chronic health conditions. *Pediatrics*. 1997;99:643–644
- American Medical Association, Council on Scientific Affairs. *Proceedings of American Medical Association House of Delegates—Report J-91. Children and Youth With Disabilities*. Chicago, IL: American Medical Association; 1991
- Maternal and Child Health Bureau, Division of Services for Children With Special Health Care Needs. *Achieving Success for All Children With Special Health Care Needs: A 10-Year Action Plan to Accompany Healthy People 2010 (Draft)*. Washington, DC: Maternal and Child Health Bureau, Division of Services for Children With Special Health Care Needs; 2001
- Betz C. Adolescents with chronic conditions: linkages to adult service systems. *Pediatr Nurs*. 1998;25:473–476
- Hallum A. Disability and the transition to adulthood: issues for the disabled child, the family, and the pediatrician. *Curr Probl Pediatr*. 1995;25:12–50
- White PH. Success on the road to adulthood: issues and hurdles for adolescents with disabilities. *Rheum Dis Clin North Am*. 1997;23:697–707
- Rosen DS. Transition from pediatric to adult-oriented health care for the adolescent with chronic illness or disability. *Adolesc Med*. 1994;5:241–248
- Rosen D. Between two worlds: bridging the cultures of child health and adult medicine. *J Adolesc Health*. 1995;17:10–16
- Appleton RE, Chadwick D, Sweeney A. Managing the teenager with epilepsy: paediatric to adult care. *Seizure*. 1997;6:27–30
- Conway SP. Transition from paediatric to adult-oriented care for adolescents with cystic fibrosis. *Disabil Rehabil*. 1998;20:209–216
- Kinney TR, Ware RE. The adolescent with sickle cell anemia. *Hematol Oncol Clin North Am*. 1996;10:1255–1264
- Rosen D. Transition to adult health care for adolescents and young adults with cancer. *Cancer*. 1993;71(suppl 10):3411–3414
- Scal P, Evans T, Blozis S, Okinow N, Blum R. Trends in transition from pediatric to adult health care services for young adults with chronic conditions. *J Adolesc Health*. 1999;24:259–264
- Watson AR, Shooter M. Transitioning adolescents from pediatric to adult dialysis units. *Adv Perit Dial*. 1996;12:176–178
- Betz CL. Adolescents transitions: a nursing concern. *Pediatr Nurs*. 1998;24:23–28
- Martin C, Nisa M. Meeting the needs of children and families in chronic illness and disease: a greater role for the GP? *Aust Fam Physician*. 1996;25:1273–1275, 1277, 1279–1281
- Sawyer SM, Blair S, Bowes G. Chronic illness in adolescents: transfer or transition to adult services? *J Paediatr Child Health*. 1997;33:88–90
- American College of Cardiology. Care of the adult with congenital heart disease: introduction. Presented at the 32nd Bethesda Conference. *J Am Coll Cardiol*. 2001;37:1161–1198
- Institute for Child Health Policy. Healthy and Ready to Work Initiative Web site. Available at: <http://www.mchbhrtw.org/>. Accessed February 21, 2002
- Institute for Child Health Policy. *Executive Summary From Transition Revolution. You Can Make It Happen in Health Care: An MCHB Invitational Meeting*. March 20–22, 1999; Savannah, GA. Available at: <http://www.mchbhrtw.org/Meetings/Transition1999/executivesummary.htm>. Accessed February 21, 2002
- Healthy People 2010 Healthy and Ready to Work Transition Work Group. *Draft 10-Year Health and Ready to Work Transition Plan*. Washington, DC: Maternal and Child Health Bureau, Division of Services for Children With Special Health Care Needs; 2000. Available at: <http://www.mchbhrtw.org/HP2010final.pdf>. Accessed February 21, 2002
- Flood R, Carson E. *Dealing With Complexity: An Introduction to the Theory and Application of Systems Science*. 2nd ed. New York, NY: Plenum Press; 1993
- Lane D, Maxfield R. Strategy under complexity: fostering generative relationships. *Long Range Plan*. 1996;29:215–231
- Lindberg C, Herzog A, Merry M, et al. Life at the edge of chaos—health care applications of complexity science. *The Physician Executive*. 1998(January-February):6–20
- McDaniel R. Strategic leadership: a view from quantum and chaos theories. *Health Care Manag Rev*. 1997;22:21–37
- Stacey R. *Managing the Unknowable: Strategic Boundaries Between Order and Chaos in Organizations*. San Francisco, CA: Jossey-Bass; 1992

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