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Implementing Transitions for Youth With Complex Chronic Conditions Using the Medical Home Model

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ABSTRACT. The concept of a medical home is endorsed as an effective model for implementing successful transitions for youth with complex chronic conditions. The U Special Kids program at the University of Minnesota is described as a medical home designed to improve service delivery for children and youth with complex medical conditions to help them achieve optimal health and functioning. Two case studies depict effective communication methods, including a concise written health history summary, that promote shared understanding of the adolescent's and family's strengths and their skills. Specific components of a transition plan are detailed with the recommendation that a formal assessment occur to develop an individualized transition plan. The individualized plan incorporates goals for the adolescent to gain independence and to obtain support in required areas. *Pediatrics* 2002;110:1322–1327; *medical home, adolescent, transition, chronic illness.*

ABBREVIATIONS. AAP, American Academy of Pediatrics; MCHB, Maternal and Child Health Bureau; USK, U Special Kids (program).

INTRODUCTION

As a matter of policy, the American Academy of Pediatrics (AAP) has stated that all children and youth with special health care needs should have a medical home, "where health care services are accessible, family centered, continuous, comprehensive, coordinated, and compassionate."¹ Simply put, a medical home means a source of ongoing, comprehensive care in the child's community. Ideally, families, health care professionals, community service providers, and other concerned people act as partners to identify and access all the medical and nonmedical services needed to help children and youth with special needs achieve their maximum potential.² The demands placed on medical home team members will often wax and wane depending on fluctuations in family stress, the medical condition, and the developmental needs of the young people involved. Patterson³ points out that family stressors related to raising children who have chronic conditions vary from day to day, and although there may be episodes of major catastro-

phe—an unforeseen hospitalization, a death in the family, loss of a job—there are also periods of relative calm. Thus, families have fluctuating needs for external supports.⁴

Adolescent years, the period of time when a child moves toward independence and often transfers to adult medical and community services, may be particularly stressful years for youth with chronic conditions and their families. Yet during adolescence, when the need for a medical home may be greatest, the adolescent and family are least likely to receive regular comprehensive care.⁵

Although the concept of the medical home was developed to apply to all children and adolescents, it may be a particularly effective model for youth with complex health conditions, especially during periods of transition. Betz⁶ describes assessment and intervention strategies that can be used to facilitate successful transitions to adult health care. The components of a health care assessment delineating specific knowledge and areas of competency for self-care for the adolescent are detailed. Rettig and Athreya⁷ describe an interdisciplinary program from pediatric to adult care for adolescents with rheumatic diseases. Collaboration with and participation by an internist and rheumatologist involved in the transition program was critical to the program's success. Pretransition planning, including assessment of readiness, is a critical initial phase of the process.

In 1996, Wagner et al⁸ pointed out that successful models for chronic conditions share common features that include: 1) the use of explicit plans and protocols; 2) the reorganization of the practice to meet the needs of patients who require more time, a broader array of services, and closer follow-up; 3) systematic attention to patient information needs and behavioral changes; 4) ready access to necessary expertise; and 5) supportive information systems. Attempts to coordinate care for young people with chronic conditions have not typically been structured as medical homes but rather based on more conventional case management models. Nurses or social workers are employed by agencies or health plans to help individuals or families appropriately access services provided by their respective systems. In at least 1 study, families of children with chronic conditions reported they have a case manager for each system with which they interface (eg, health, social services), with each case manager trying to ration services for

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their respective agency rather than assisting families in accessing necessary care.⁹

BACKGROUND

In 1990, The Maternal and Child Health Bureau (MCHB) and the AAP created the "Communities Can Campaign" in an effort to support communities attempting to develop family-driven systems of care for children with special needs.¹ One of the 4 major goals identified for a well-developed community system was "to find a way to help families coordinate services and for the system to coordinate itself." More than a decade later, families who have children with complex medical conditions still identify lack of coordination between disparate service systems as a major source of stress.⁸

In 1992, the AAP recommended that the primary care provider play a key role in ensuring that children and youth with special health care needs have a medical home.¹ Such a medical home would provide comprehensive, integrated services which are essential elements for family-centered care. Within a medical home, the focus of care shifts from acute illness management to primary health care that includes care of the child in the home and community. This approach has taken on more of a developmental perspective, emphasizing preventive health care and early intervention for children and youth with special needs. In addition, physicians are encouraged to become familiar with community resources designed for children with special needs and how to access them.¹⁰

Family-centered care, health care reform, and the movement toward managed care have provided an added impetus for the medical home concept. Combining models of managed health care with the medical home model for children with special health needs has the potential for increased financial accountability while still ensuring that children with special needs receive quality, comprehensive medical care.^{1,2} Unlike many health conditions with which services are received within a single system of medical providers, children and youth with special needs often receive services from a varied network of programs and resources that include medical, educational, and social systems. The challenge is to provide comprehensive services in the communities and to coordinate care and services across these complex systems. Children, youth, and families benefit when services are integrated and coordinated. Unfortunately, services more often are uncoordinated, episodic, fragmented, or duplicated; have different eligibility requirements and application forms; or are simply unavailable.^{11,12}

Complexity of Needs Varies

The delivery of health care to children, adolescents, and young adults changes as the individual and members of the family enter new developmental stages or accomplish additional individual and family developmental tasks. Components of the medical home need to change accordingly. Even in the midst of change, however, the core of the medical home model for children and for adolescents is the indi-

vidualized care plan tailored to the specific skills and needs of each adolescent. Such a plan will reflect the relative complexity of the young person's condition, family system, health care history, and educational expectations and goals.

Assessment of Complexity of Needs

Within the medical home model, there is collaboration and partnership between primary, specialty, and subspecialty providers as well as community providers and programs serving youth with special health care needs and their families. The medical home model promotes development of a team that is capable of identifying an individual's strengths and abilities, coordinating complicated information, and managing barriers so that a young adult can make a successful transition to community living. The definition of that success is tailored to the limitations and assets of the young person. As the youth's situation becomes more complex, the medical home team will need to adapt the transition plan to ensure it will continue to be effective. By understanding the relative complexity of a teenager's needs within the domains of the family, health care, and education systems, the appropriate partners can take the lead in the arenas of concern.¹³

The importance of collaboration between the adolescent/young adult, family members, educational, social service, and health care professionals is implicit in the medical home model.¹⁴ Health care providers are generally aware, at least at an abstract level, of issues related to the transition from school to work as well as transition from home to independent living; these are 2 critical elements that influence the quality of life for a young adult.¹⁵ The primary care provider can assist in the transition planning process by providing information to other team members about the individual's special health needs as they relate to independent living, educational, and vocational issues.²

So much depends on the youth and his or her medical condition. The less complex the condition, the less the need for complicated medical protocols and the greater the likelihood of a young adult developing the competencies needed to achieve self-sufficiency for health self-care management.^{6,14} Transferring responsibility for self-care to the adolescent is a complex process that requires assessment of a variety of factors, including knowledge, performance, cognitive complexity, health locus of control, family factors, and perceptions.¹⁶ As the complexity of needs increases, it may be necessary to designate responsibility for certain components of care management to others. For example, a young adult with a single condition who is rarely ill, has been successful with managing his care plan, is of normal intelligence, and accepts and understands his condition will need little medical involvement in moving into adult health care and into the adult world of employment and relationships. Transition should be straightforward, given a moderately strong family and conventional education needs. As with most of his or her peers, the bulk of the responsibility for successful transitions will be with the young person,

the family, and the community. However, it should be noted that although those who have minimal impairments are most likely to functionally transition to adult roles and responsibilities needing minimal resources, they might sustain more emotional sequelae from their condition and the social isolation they may have engendered throughout adolescence than their more involved peers.¹⁷

As the assessment of a teen's health status becomes more complex, the transition issues become more complex and there are more barriers between pediatric and adult health care, thus making medical transfer more difficult. Barriers to successful transition from adolescent to adult health care have been well documented and include philosophic differences, readiness, and economic issues in addition to issues relating to the caregiver's knowledge and skills in the area of an individual's special needs (see the article by Reiss and Gibson in this supplement).¹⁸ Again, the more complex a young person's needs, the greater the likelihood of there being real and perceived barriers to successful transition. Complexities may include: severity of illness or disability, level of maturity, acceptance and understanding of the patient, environmental and family stresses, need for control by parent or health care provider, perception of potential outcomes for the individual, and lack of support systems for the patient and family.¹⁸ Low expectations by parents and others who are significant to the individual with special needs, lack of knowledge of career and vocational education services, and lack of self-advocacy skills can also impede the transition process.¹⁴

Barriers to care coordination are also potential barriers to transition. These include lack of knowledge about community resources or the coordination process, lack of communication among health care professionals and organizations involved in the child's care, extra time and effort necessary to provide coordination of services as well as lack of reimbursement for this time, and the existence of multiple care coordinators without clear delineation of roles.³

A Medical Home Model for Children and Youth With Complex Chronic Conditions

The U Special Kids (USK) program in the Division of General Pediatrics and Adolescent Health at the University of Minnesota has been nominated as a best practice program by the Medical Home Initiative Project Advisory Committee. Since 1996, USK has provided a medical home designed to improve the service delivery system for children and youth with complex medical conditions and to help them achieve optimal health and functioning. USK provides medical case management services that conform to the integrated model of effective chronic illness care.⁹ Care is family driven with the goal to increase the participation, confidence, and skills of parents who must manage the care of a child or youth with a very complex medical condition and is based on the belief that productive interactions yield improved functional and clinical outcomes.

The program's mission is to help children and youth with complex conditions and their families

stay as healthy as possible by coordinating care and addressing medical issues in a rapid preemptive (rather than reactive) fashion. The program provides a nurse coordinator and pediatric nurse practitioner who are both readily accessible by telephone to triage acute illnesses or problems and are available as an information resource for families. Along with a secretary, they help coordinate and properly sequence multiple tests, procedures, and appointments. A pediatrician and the pediatric nurse practitioner collaborate with specialists and oversee the comprehensive medical care and the development of medical management plans for recurrent acute illness episodes. This type of intense care coordination is an integral component in the context of successful medical homes,^{2,3} and a key to the success of the USK program. Following are 2 sample cases that illustrate how the medical home team can facilitate the transition process for youth with complex chronic conditions.

CASE REPORTS

Case 1

Jane is an 18-year-old female with a high-level myelomeningocele whose major chronic problems include paraplegia, hydrocephalus, developmental delay, hearing loss, recurrent urinary tract infections, dysmenorrhea, and migraine headaches. Her medical devices include a ventriculo-atrial shunt that was placed shortly after birth to treat her hydrocephalus, a feeding gastrostomy tube, and a central venous catheter for frequent blood draws and intravenous antibiotics. She has a history of severe reactions to several medications, as well as to tapes, topical creams, and latex. She lives at home with her parents on a farm 120 miles from the university medical center. She attends school 3 days a week and uses an electric wheelchair for mobility. She has in-home nursing care 12 hours per night by skilled nurses. A local physician assists with some of her primary medical care, but most medical care is provided at the university. The USK program collaborates with the university specialists and local physician to deliver coordinated services. Jane's family has been reluctant to transition to adult services because of the complexity of Jane's medical needs and familiarity of the pediatric specialists and hospital nursing staff with her complex routines.

Jane was seen by her local physician, who initiated an oral antibiotic when she had yet another urinary tract infection. Two days after beginning the antibiotic, Jane began vomiting and developed profuse diarrhea and symptoms of dehydration. The local physician contacted the USK physician to discuss transfer to the university for admission and management. There were no beds available on the pediatric ward, and Jane's family was concerned that if she were admitted to the adult ward, her caregivers would not be familiar with Jane's special needs. The USK physician discussed the situation with the internist covering the adult ward service who admittedly was unfamiliar with Jane's case and complex care needs. It was agreed that Jane would benefit from comanagement by the internal medicine team with close consultation from USK. The USK program provided the ward team with a typed summary of critical information related to Jane's medical history, medications, adverse medication reactions, and daily routine cares (see Fig 1 for prototype report). The team also provided the nursing staff with a detailed written summary of Jane's home nursing care plan and arranged a meeting between Jane's pediatric primary nurse and her new primary nurse on the adult ward.

Jane was admitted to the adult ward. An intravenous antibiotic that Jane had not reacted to previously was chosen on the basis of the medical history provided by USK. The hospital course was uneventful, and Jane was discharged from the hospital after 5 days. Arrangements were made to continue the intravenous antibiotics at home for another 5 days. The USK team continued to coordinate Jane's care after discharge by reviewing laboratory data and establishing regular telephone communication with her

Simple	Complex
Adolescent's Condition	
• Single condition	→ Multiple conditions
• Rare acute illnesses	→ Technology/dependent, frequent life-threatening acute illnesses
• Few medications	→ Multiple medications or allergies to medications
• No cognitive impairment	→ Profound mental retardation
• No physical impairments	→ Physical impairments
• Mentally healthy	→ Mentally ill
• No behavioral concerns	→ Serious behavioral issues
• No extenuating circumstances	→ Stressful extenuating circumstances
Family Strengths	
• 2-parent family	→ Single parent
• Support from extended family, friends and community (natural supports)	→ No family support (few or no natural supports)
• Some support from service providers	→ Reliance on support from service providers
• Family effective at developing positive collaborative relationships with providers and accessing needed services	→ Family ineffective at developing collaborations and accessing needed services
• A single source of affordable insurance that covers all adolescents needs	→ Uninsured, underinsured or multiple payers of services
• Stable housing, employment and transportation	→ Unstable housing, employment and transportation
Health Care	
• Single primary care provider who can manage condition	→ Multiple subspecialists
• No surgeries	→ Multiple surgeries
• No hospitalizations	→ Multiple hospitalizations
• No nursing care needs	→ In-home skilled nursing & special equipment and supplies
Education	
• Mainstream	→ Special education services

Fig 1. University of Minnesota's USK complexity of needs assessment.

home care nurses. Jane was scheduled to follow-up with the internal medicine clinic 2 weeks after discharge.

Jane's successful admission to the adult service was facilitated by collaboration among the different specialists and provision of detailed, specific, and written medical information. Fundamentally, transition planning is an interpersonal process based on communications. One of the major limitations we have found in the transfer of complex pediatric patients to adult providers is the complexity and size of their medical charts. A clear and accurate synthesis greatly facilitates the process and allows the adult provider to receive a complicated patient with more confidence than would otherwise be possible. The process involved multiple levels of communication so that a seamless transfer of care could occur. The primary nurse was a key person in Jane's hospital care. Shared documentation and communication between the pediatric and adult primary nurses facilitated a smooth transition. Finally, as a result of gradual, coordinated transfer, Jane and her family were able to embrace the process with less fear. There was a successful outcome to this hospitalization. The process of saying "thank-you" and "good-bye" to nurses and pediatric providers who had weathered many stormy days with Jane and her family could now begin.

Case 2

John is a 19-year-old male with multiple chronic conditions that are the result of a brain tumor, chemotherapy, and cranial radiation. He has a history of frequent hospitalizations, central apnea that requires a tracheotomy and ventilator, gastrointestinal dysmotility, headaches, mood swings, and episodes of inappropriate behavior. He uses a motorized wheelchair and attends school part-time. John lives with his mother in an apartment and receives 18 hours per day of home nursing care.

The opportunity arose for John to move to a group home with full-time supervision by skilled nurses and the services of a personal care attendant. The social worker and the residential facility administrator, however, were concerned about their capacity to

care for his complex needs. John's mother wanted to see him move, because it represented a step toward adulthood; however, she was afraid that he might lose the continuity of care that she had been coordinating.

The USK team first worked to develop a concise, comprehensive medical profile from the numerous volumes of John's medical record information. Medical records from his hospitalizations and subspecialty outpatient visits and a variety of other service provider records, such as mental health services and rehabilitation therapies, were reviewed for pertinent information and synthesized into a coherent document. When completed, a copy of the medical profile was given to John's mother as well as all pediatric specialists who were involved in his care for each to review for accuracy and omission of critical information. Copies of the final document were distributed to the mother, group home, residential supervisor, hospital children's ward, emergency department, and medical home team to promote consistent and coordinated care. The comprehensive health care profile provided a document of consistent information for all involved in John's care. John's variable behavior and mood impacted his ability to participate in health care decisions at times. Before John's transfer to the group home, a team meeting was held that involved the USK team, family, and group home staff. The meeting provided a forum for expressing concerns and mutual problem solving. As a result, an agreed on, individualized care plan for John was developed before his move.

The providers and USK staff were aware of issues of control that occur when an individual moves from home to a new setting. Staging a transition from home to a community setting, in this case, allowed the family's goals to be met in a less stressful and planned manner.

DISCUSSION

Clearly, communication and information sharing strategies are at the heart of these 2 cases. They

highlight the 4 features Wagner et al⁸ identify as essential to the success of comprehensive care systems. Providing accurate written information about the individual's health care condition is imperative to continuity and coordination of care. In theory, within the medical home are accessible, comprehensive, central records that are maintained and contain pertinent information about the adolescent in a confidential manner.¹³

Medical homes by their very definition rely on the fundamental principles of family-centered care. Shelton¹⁹ has identified the beliefs and behaviors that are critical to forging empowering partnerships: "There must be a fundamental commitment on the part of the provider to a helping style that truly embodies partnerships, a bone-deep commitment to partnership, to creating opportunities at every juncture for families to take the role they choose, and to providing them with the skills, information and support to do so. . ."

Transition is an ongoing developmental process that requires regular attention, especially for youth with the most complex health and family circumstances.

The Medical Home: Components of Transition Within the Model

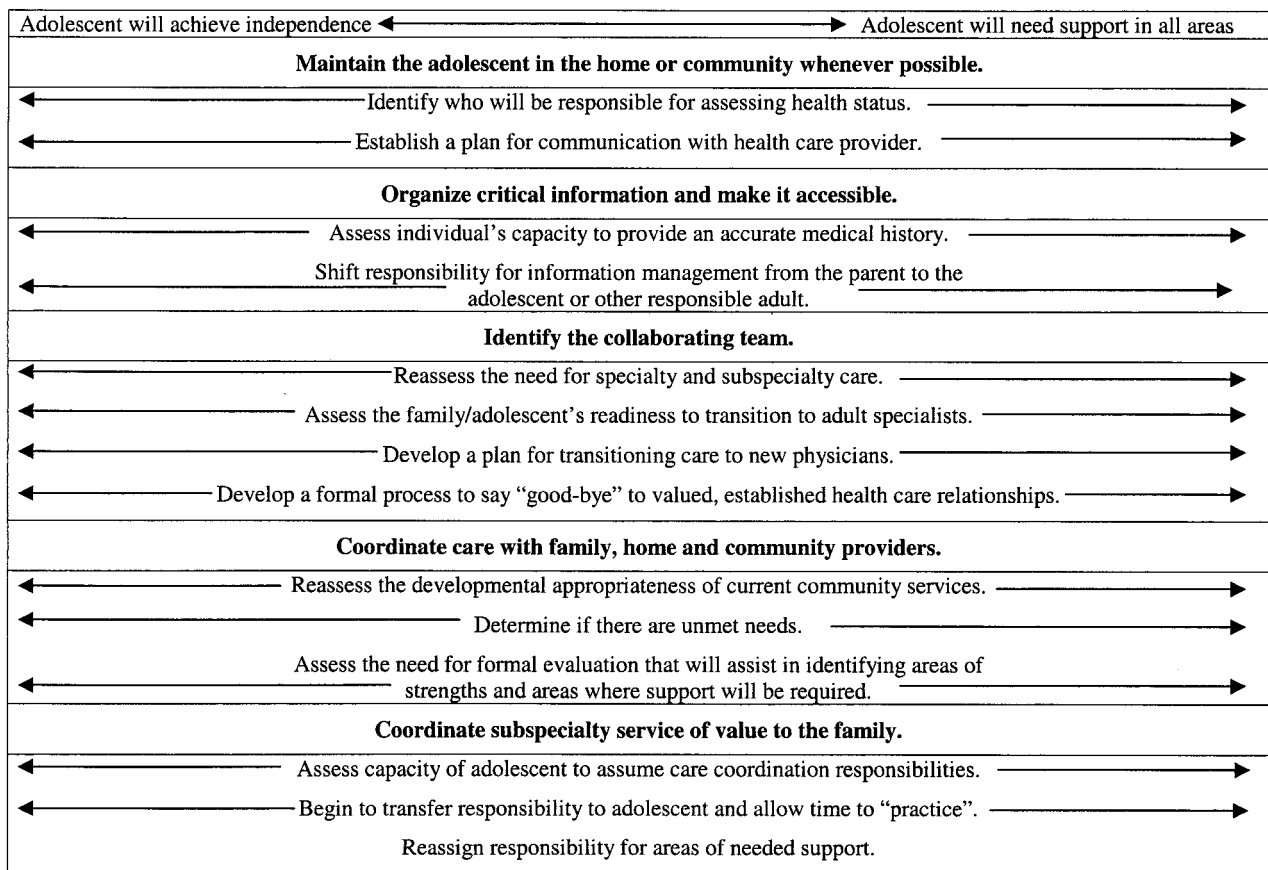
Ideally, the medical home provides the same coordination during transition as it does throughout the

child's life. The medical home concept is based on developmental needs of the individual and family being served. We would suggest that the core elements of a medical home for children and young adults are the same, a written summary of critical information, collaborative team, and a process to coordinate and integrate services delivered.

What distinguishes the medical home for young adults is the need for a more formalized shifting and reassignment of roles and responsibilities. It is paramount to assess the understanding of adolescents and young adults as related to their health care condition, their capacity for medical decision-making, and their ability to participate in and manage their own care. Medical home provider training should be provided that enhances adolescent transitions to independence and identification of areas where support will be required.

A medical home for the adolescent or young adult should ensure that comprehensive coordinated care is delivered. Figure 2 outlines the medical home regardless of the individual's developmental age and provides specific examples of actions that would support transition from child-focused to adult-focused care.

Although the trajectory for transition to adult health care for individuals without special health care needs occurs in a more natural, "as-needed" basis, the transition of an adolescent with special



The components of transition within a medical home for an adolescent or young adult in a medical home look very similar to the components of the medical home for a child. The needs are on a continuum based on the skills and abilities of the adolescent.

Fig 2. Components of transition within the medical home model.

health care needs, especially those whose conditions are more complex, must be more carefully planned. The parent, adolescent, or persons participating in the care of an adolescent with special health care needs must make a conscious effort to develop a plan that moves an individual from child-centered to adult-centered care. Such a plan provides a system for making ongoing changes as they occur with the individual's health care status, their health care needs, or their support systems, altering the delicate balance needed for day-to-day management.

The medical home model is philosophically aligned with providing an individualized process of transition and is less likely to merely transfer care for the adolescent at a predetermined age.²⁰ The team members are invested in the successful outcome for the young adult, much like schoolteachers are invested in successful graduation from high school. Indeed, in the medical home model, the adolescent, family, and health care and community providers form a partnership. Cooley⁴ says "those who are surrounded by empty rings of natural and informal supports and have only formal supports are destined to remain dependent on those formal supports are at high risk for social isolation and demoralization." Adolescents who have a medical home have the best of both worlds: those who provide formal support collaborate with those who provide informal support. The outcomes of such collaboration are more likely to be transitions that meet the individual needs of the adolescent and support the adolescent in becoming part of the larger adult community.

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