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Supporting the Health Care Transition From Adolescence to Adulthood in the Medical Home

American Academy of Pediatrics, American Academy of Family Physicians, and American College of Physicians, Transitions Clinical Report Authoring Group

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Guidance for the Clinician in Rendering Pediatric Care

Clinical Report—Supporting the Health Care Transition From Adolescence to Adulthood in the Medical Home

abstract

Optimal health care is achieved when each person, at every age, receives medically and developmentally appropriate care. The goal of a planned health care transition is to maximize lifelong functioning and well-being for all youth, including those who have special health care needs and those who do not. This process includes ensuring that high-quality, developmentally appropriate health care services are available in an uninterrupted manner as the person moves from adolescence to adulthood. A well-timed transition from child- to adult-oriented health care is specific to each person and ideally occurs between the ages of 18 and 21 years. Coordination of patient, family, and provider responsibilities enables youth to optimize their ability to assume adult roles and activities. This clinical report represents expert opinion and consensus on the practice-based implementation of transition for all youth beginning in early adolescence. It provides a structure for training and continuing education to further understanding of the nature of adolescent transition and how best to support it. Primary care physicians, nurse practitioners, and physician assistants, as well as medical subspecialists, are encouraged to adopt these materials and make this process specific to their settings and populations. *Pediatrics* 2011;128:182–200

1. INTRODUCTION AND METHODOLOGY

With reasonable biological certainty, most adolescents transition to adulthood. There is much less certainty about the manner in which health care professionals support this transition. Transition planning, when present at all, can be inexplicit, incomplete, or late, and when necessary, the transfer of care to an adult medical home and to adult medical subspecialists involves more of a drift away from pediatric care rather than a clearly planned and executed handoff. In 2002, a consensus statement coauthored by the American Academy of Pediatrics (AAP), the American Academy of Family Physicians (AAFP), and the American College of Physicians (ACP)-American Society of Internal Medicine was published, stating the importance of supporting and facilitating the transition of adolescents with special health care needs* into adulthood.[1] This statement represented the shared perspectives of health care professionals, families, youth, researchers,

*The Maternal and Child Health Bureau (MCHB) defines children and youth with special health care needs as "[t]hose who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally."[21]

AMERICAN ACADEMY OF PEDIATRICS, AMERICAN ACADEMY OF FAMILY PHYSICIANS, AND AMERICAN COLLEGE OF PHYSICIANS, TRANSITIONS CLINICAL REPORT AUTHORING GROUP

KEY WORDS

health care transition, youth transition, medical home, children with special health care needs, primary care, adolescent health, quality improvement

ABBREVIATIONS

AAP—American Academy of Pediatrics
MCHB—Maternal and Child Health Bureau
CCM—chronic condition management
EHR—electronic health record

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The guidance in this report does not indicate an exclusive course of treatment or serve as a standard of medical care. Variations, taking into account individual circumstances, may be appropriate.

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and policy-makers. It provided foundational guidance for health care processes that include health care planning and information exchange, for professional education and certification, and for insurance and payment reform. Its conclusions and critical steps remain widely accepted standards that have informed the development of pilot projects, model practices, and national initiatives to improve support for transitioning youth. The US Department of Health and Human Service's Maternal and Child Health Bureau (MCHB) has been instrumental in promoting the importance of seamless, effective, and comprehensive services for all youth and families during this major life transition.[2]

After nearly a decade of effort, widespread implementation of health transition supports as a basic standard of high-quality care has not been realized. To date, only limited progress can be documented in the achievement of the consensus statement's 6 critical steps. Although 2 National Surveys of Children With Special Health Care Needs indicate improvements between 2001 and 2006, there has been only limited achievement of national health policy goals related to transition.[3,4] Outcomes-related research efforts have, so far, failed to fully address the transition needs of adolescents with or without chronic conditions.[5] A recent national survey revealed that pediatricians remain poorly informed about the conclusions of the consensus statement and that most pediatric practices neither initiate transition planning early in adolescence nor offer transition-support services, which have been found to be critical for ensuring a smooth transition to the adult health care model.[6] The survey authors noted that "gaps in transition support are due in part to limited staff training; lack of an identified staff person responsible for transition; financial barriers; and anxiety on the part of pediatricians, adolescents, and their parents about planning for their future health care."[7] Other authors have cited the lack of developmentally appropriate tools for assessing child and family readiness for transition as a barrier to transition.[8,9]

The result is that many pediatricians, youth, and families have found a limited availability of adult providers with whom to arrange a smooth transition of care.[10–14] In addition, evidence indicates that many adult providers feel unprepared to care for young adults with complex chronic conditions. In some cases, there is no identified adult primary care or specialty provider to whom care can be transitioned. Lack of time, adequate payment, and training have been cited as major barriers to transition.[15] Workforce shortages exist and are anticipated to worsen for physicians and other health professionals providing care for adults of all ages. In the face of an aging population that needs care, these shortages may be an obstacle to the delivery of primary care to more young adults with or without special health care needs.[16]

Family physicians caring for youth note that no transfer of primary care will be needed; nevertheless, there is a need to implement an adult model of care; plan for the transfer of specialty care to adult medical subspecialists; and support broader transition planning that includes issues such as educational attainment, career choices, and independent living needs. Internists find it challenging to care for a child or youth with special health care needs when the youth lacks preparation to be his or her own health advocate and the referring physician sends only minimal information about the youth and/or his or her condition.[17] Despite the recent spread of the family-centered medical home model for the redesign of primary care, payment reforms for non–encounter-based services (such as transition planning and care coordination) still have not materialized to a significant degree. Finally, with relatively few model practices exemplifying high-quality transition supports, training providers in the principles of health care transition remains challenging.

When there are obstacles, there are also opportunities. The need is stronger than ever for the seamless transfer of care and personal health information from pediatric care settings to more adult settings and for all youth to function as independently as possible in promoting their own health as adults. The 2007 AAP Annual Leadership Forum designated the resolution "transitioning youth with special health care needs to adult health care" as a top-10 priority. *Bright Futures* provides a framework for anticipatory guidance throughout childhood and adolescence that encourages parental support of self-management and independent decision-making about health.[18] Explicitly planned care as the product of a partnership among health care professionals, youth, and families has become an essential characteristic of the primary care medical home for which recognition standards have become more firmly established, such as the Physician Practice Connection for the Patient-Centered Medical Home of the National Committee on Quality Assurance and the Medical Home Index of the Center for Medical Home Improvement.[19,20] Providing high-quality transition care and support may become one of the standards that both pediatric and adult primary care practices would need to meet to be recognized as a medical home and become eligible for new payment scenarios.

These new opportunities have set the stage for a reaffirmation of the principles in the original consensus state-

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ment by the AAP, American Academy of Family Physicians, and American College of Physicians. All 3 professional groups also recognize the need to translate those principles into practical operational guidance for the care of all children and youth as they transition to adulthood. Although youth with special health care needs require a broader range of considerations during their transitions, all youth need education, guidance, and planning to prepare to assume appropriate responsibility for their own health and well-being in adulthood.[21] Most youth with chronic illnesses will survive into adulthood and, depending on the severity and specifics of their disability, should transition to an adult model of care. After the age of majority,† all youth deserve to be treated as adults and to experience an adult model of care, although some people may require decision-making support from a third-party proxy, such as through guardianship or power of attorney. Recent evidence has shown that higher executive function affecting impulsivity and decision-making continues to mature through the mid-20s. Older adolescents and young adults may require guided decision-making assistance from clinicians and family members as they enter adult systems of care.[22] Nevertheless, most youth will benefit from advance planning and preparation for that experience regardless of whether they remain with their pediatric provider or medical subspecialist after the age of 18.

This report assumes that it is the youth, not the clinician, who is transitioning in his or her movement from one stage of life and development to another. The actions of the youth's medical home involve not the transition of care but, rather, the transfer of some or all elements of care to an adult medical home setting or, in the case of a family medicine medical home, to an adult medical home model. The medical home visit is a different process when the patient has reached the age of majority; adult patients have specific considerations and necessitate providers' attention to new requirements such as adopting consent for treatment processes and Health Insurance Portability and Accountability Act (HIPAA)–compliant forms. Health care transfer is an element of transition and has a defined end point that may vary from patient to patient. Because both transition and transfer are influenced by environmental, socioeconomic, medical, and other factors, it is the responsibility of the medical home—in partnership with patients and their families—to coordinate efforts that ensure optimal outcomes for every patient.

The patient- and family-centered medical home model of primary care includes 3 distinct but interrelated care processes: preventive care; acute illness management; and chronic condition management (CCM). CCM constitutes an explicit and defined approach that involves planned and proactive care rooted in evidence- and consensus-based guidelines, written care plans, and active care coordination. The medical home uses a registry to track the status of its patients with special health care needs and may stratify the registry in terms of the severity or complexity of the patient's condition. Those with more complex conditions may be identified for written care plans, care coordination, and a more intense, amplified transition plan. CCM also includes an explicit approach to comanagement with medical subspecialists in which the roles of primary and specialty care are clearly articulated. (Comanagement involves an explicit and transparent process in which providers involved in a patient's care determine—in collaboration with the patient or family—which provider will be responsible for which aspects of the patient's care. Comanagement can occur between primary care providers and 1 or more medical subspecialists. It might also occur during the transfer of care from a pediatric to an adult setting.) Transition activities for youth with special health care needs should include a comanagement-transition plan that articulates the process and timing for the transfer of care from pediatric to adult medical subspecialists. (These components of CCM are described in greater detail later in this report.)

This clinical report aims to advance the practice-based implementation of planning, decision-making, and documentation processes for youth who are approaching transition, including those who have special health care needs and those who do not. It intends to provide a structure for training, continuing education, and research to further the understanding of best practices for transition of adolescents to adult care. It does not detail the activities conducted by receiving providers who accept patients into an adult model of medical home care. Because there is currently only limited outcome literature about transition, this clinical report is based on expert opinion and consensus recommendations rather than on specific evidence. The report provides a decision-making algorithm (Fig 1) for all youth, beginning at 12 years of age. The algorithm includes a branch with expanded, generic guidelines for transitioning youth with special health care needs who require CCM.[23] These chronic condition guidelines can, in turn, provide a template for later, more detailed, and specialized applications of the algorithm to specific conditions and specialty care

†The "age of majority" is a legal definition of the age at which a person is considered to be an adult. In most states, this age is 18 years; exceptions are Alabama and Nebraska (19 years) and Washington, DC, and Mississippi (21 years).

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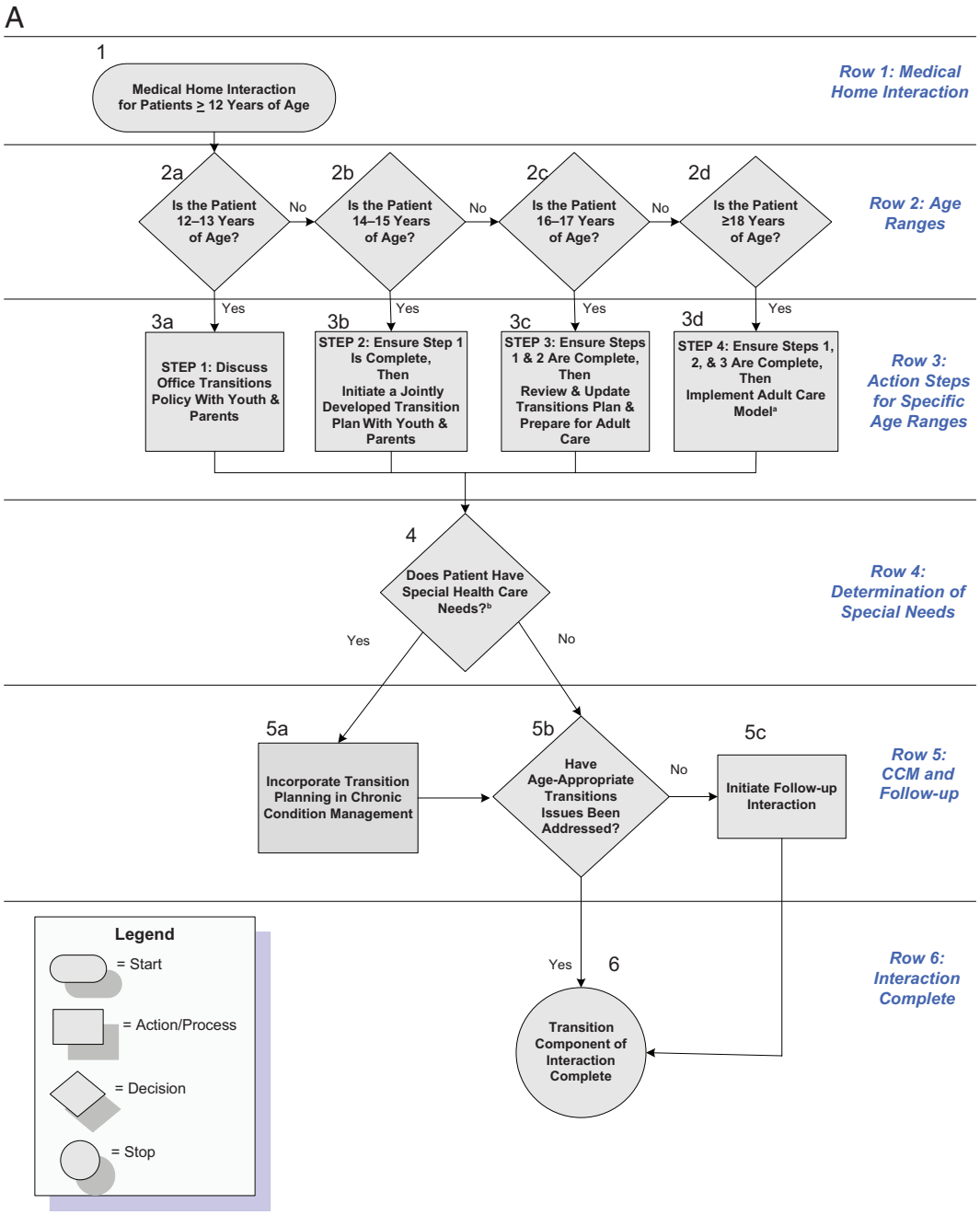

FIGURE 1

A, Health care transition-planning algorithm for all youth and young adults within a medical home interaction. [a] For pediatric practices, transfer to adult provider; [b] the MCHB defines children with special health care needs as "[t]hose who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally." B, Reverse side of the algorithm.[21]

situations. These guidelines, recommendations, and resources will also be useful to the medical subspecialist engaging in the transition process; primary care providers and medical subspecialists are encouraged to make this process specific for their own needs.

Methodology

The AAP and the National Center for Medical Home Implementation (a cooperative agreement between the AAP and the MCHB) have prioritized the issue of transitioning youth from a pediatric to an adult medical home with the goal of facilitating the effective transition of all youth from pediatric to ap-

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ALGORITHM COMPONENT	DESCRIPTIVE TEXT
Medical Home Interaction for Patients ≥12 Years of Age	***1.*** Initiate first step in the health care transition planning process at age 12.
Is the Patient 12–13 Years of Age? / Is the Patient 14–15 Years of Age? / Is the Patient 16–17 Years of Age? / Is the Patient ≥18 Years of Age?	***2a, 2b, 2c, 2d. Age Ranges.*** By age 12, conduct surveillance to assess any special health care needs. Start actual transition planning by age 14. By ages 16–17, transition planning should be well established. At age 18, initiate an adult model of care for most youth, even if there is no transfer of care. If transition planning does not occur on the schedule described by the algorithm, a concentrated effort is required (eg, special visits) to complete the process successfully.
STEP 1: Discuss Office Transitions Policy with Youth & Parents	***3a.*** Every practice should have a written transition policy that is prominently displayed and discussed with youth and families. The policy should explicitly state the practice's expectations and care process for the health care transition of their adolescent patients to an adult model of care.
STEP 2: Ensure Step 1 is Complete, then Initiate a Jointly Developed Transition Plan with Youth & Parents	***3b.*** The practice should use a standard transition plan that can be adapted for each patient's needs. This tool should include components to obtain an accurate assessment of the patient's ability to transition successfully. Providers should interview youth and family members to identify needs and assess the intentions and motivations for youth independence.
STEP 3: Ensure Steps 1 & 2 are Complete, then Review & Update Transitions Plan & Prepare for Adult Care	***3c.*** Transition plans must be reviewed regularly and updated as necessary. The provider must also perform surveillance for changes in the youth's medical status and address youth and family concerns that may warrant changes in transition goals. Failure to achieve transition-readiness goals warrants reevaluation of the existing plan and increased frequency of medical home interventions/visits. A "pretransfer" visit to the adult medical home could be conducted during the year before the transfer.
STEP 4: Ensure Steps 1, 2, & 3 are Complete, then Implement Adult Care Model* **for pediatric practices transfer to adult provider*	***3d.*** Transition to an adult model of care occurs appropriate for youth's developmental level, which is followed as appropriate by transfer to an adult medical home. Complete medical records should be delivered to the adult provider, along with a portable summary, which is also provided to the patient or guardian. For children and youth with special health care needs, direct communication between pediatric and adult providers is essential, because adult medical personnel may be unfamiliar with certain pediatric conditions.
Does Patient Have Special Health Care Needs?**	***4.*** Transition planning for children and youth with special health care needs should include specific CCM activities such as use of registries; care plans; care coordination; CCM office visits; and comanagement with medical subspecialists. Transition goals must be individualized to account for variations in the complexity of a youth's condition and in the youth's intellectual ability and guardianship status.
Incorporate Transition Planning in Chronic Condition Management	***5a.*** Youth with special health care needs require an expanded transition-planning process. Transition planning in CCM includes addressing the exchange of complex health information; competencies for self-care; transfers of specialty care; and issues related to insurance, entitlements, guardianship, and eligibility for adult services. In a medical home, such youth may have a written care plan as part of the medical record. At age 14, this plan should include a section titled "transition plan," which should be expanded and developed as the youth approaches age 18 and beyond.
Have Age-Appropriate Transitions Issues Been Addressed?	***5b.*** Use of transition-planning tools and readiness checklists facilitate the provider's ability to ensure that all age-appropriate transition issues have been addressed. Each action step must be completed in order, even if it means the provider has to schedule specific visits to initiate and complete steps missed earlier in the process to catch up before the next visit.
Initiate Follow-up Interaction	***5c.*** Focused tasks involving little detail or complexity can be addressed by the medical home care coordinator, medical provider, or other appropriate staff through telephone or electronic media. More complex issues may necessitate face-to-face office visits.
Transition Component of Interaction Complete	***6.*** The provider is finished with the transition tasks for that specific interaction or visit; transition planning is an ongoing activity that occurs at every interaction.

FIGURE 1
Continued.

propriate adult care. The Executive Committee and staff of the AAP Council on Children With Disabilities (COCWD) are leading the transitions initiative, which has received funding support from the National Center for Medical Home Implementation and the COCWD. The ultimate goal of this initiative is to help medical home providers, patients, and their families ensure a successful transition to appropriate adult care.

In 2008, the AAP convened a meeting to review and provide advice on proposed transition initiatives. Current literature and activities were highlighted, and areas in which assistance is needed for pediatric providers to properly address transitioning youth to adult care within their practice were identified. The first activity of the transitions initiative was to develop a clinical report to provide pediatric providers with the information they need to facilitate youth receiving high-quality, developmentally appropriate health care services as they transition to adulthood. A Transitions Clinical Report Authoring Group was subsequently assembled and cochaired by Drs Carl Cooley and Paul Sagerman. Other disciplines and/or groups represented on the authoring group include pediatric primary care and subspecialty physicians, adult health care providers, family members, and a young adult who recently completed his own health care transition.

These stakeholders partnered to develop this clinical report on the importance of youth receiving high-quality, developmentally appropriate health care services as they transition to adulthood. It provides practitioners with a clear time line and algorithmic protocol for succeeding in this process. A draft version of this clinical report underwent extensive peer review by committees, councils, sections, and additional groups within the AAP as

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well as by external people or groups who were either identified as experts in the field or had requested the reviewing opportunity. The resulting comments were incorporated into the report, as appropriate. It is expected that all subsequent AAP transition initiatives will use the publication of this clinical report, and the guidance therein, as a foundation for education, training, and quality measurement.

2. GETTING READY FOR TRANSITION

Transition planning should be a standard part of providing care for all youth and young adults, and every patient should have a transition plan regardless of his or her specific health care needs. Successful transition involves the engagement and participation of the medical home team (physicians, nurse practitioners, physicians assistants, nurses, care coordinators), the family and other caregivers, and the individual youth collaborating in a positive and mutually respectful relationship (ie, one that honors diversity and is consistent with each family's cultural and religious beliefs). The medical home team does not engage in transition planning alone; rather, it jointly creates and implements the plan with the youth and his or her family/caregivers. The medical home team facilitates a process that is planned, smooth, and patient- and family-centered. The parents' role is to actively engage in the process and move in and out of the decision-making position as appropriate. The youth's role is to maximize his or her independence and primacy in the decision-making process to foster lifelong functioning and self-determination. The receiving adult providers also need to be identified and engaged and, as needed, to provide developmentally appropriate support for the family and young adult during the transition process. This process is described in both the algorithm and "Adult Medical Home (Receiving Provider): Roles and Responsibilities."

a. Provider Readiness

A key component of supporting the transition process is the primary care medical home having an explicit office policy that describes the practice's approach to health care transition, including the age and process at which youth shift to an adult model of care. This office policy applies to all youth (both with and without special health care needs), guides the process, and helps the youth and family members (or other caregivers) understand both their and the medical home team's roles and responsibilities. The office transition policy should be visible and readily available to patients and their families, including depicting them in brochures, posters, and/or Web-based information about the practice. This office policy should clearly describe the goal of transition as part of lifelong preparation for a successful adult life and articulate how transition planning facilitates the patient's movement from a pediatric to an adult care mode.[17] Additional components of the office policy are described later in the algorithm.

To achieve the goal of transition planning as a standard of care, the medical home team must receive training and technical assistance to implement transitions effectively and adopt transition-related practices (eg, discussing the office transition policy, assessing family and youth transition readiness, developing referral relationships in the adult care system). Adult medical homes and medical subspecialists may need to build their capacities to provide services to young adult patients, particularly those with cognitive impairments and other special health care needs. Education and clinical experience for medical home team members will provide essential skills for the successful transition of youth both with and without special needs. Issues of provider readiness are described further in "Adult Medical Home (Receiving Provider): Roles and Responsibilities."

b. Family Readiness

The medical home team members must understand and address patients' and parents' perspectives and needs during transition and recognize that this process is complex and potentially emotional for parents and other caregivers/guardians. Although families make multiple transitions during their children's lives, for many parents, the pediatrician has been a constant, and they may find transition from the known to the unknown to be stressful. This is particularly likely to be true for parents of children with special health care needs. To make the process smoother for all involved, transition planning must anticipate and address challenges that parents may face as the youth enters adulthood.

It is important for physicians and other health care professionals to engage parents and youth with education and information about their role in the transition process. This education should include information about how the health care environment changes when the youth legally becomes an adult at 18 years of age as well as differences between pediatric and adult medicine models. The provider's goals are to normalize the transition process, address the families' anxieties or questions, and foster a team approach to help facilitate the acquisition of skills and tools that the youth can use both in transition and beyond. The family members or other caregivers should be engaged and open to the process (eg, learning about any upcoming changes in health coverage), encourage autonomous decision-making

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and self-care on the part of the youth, and share their questions and/or concerns with the provider as they adjust to their role shifting from primary decision-maker and caregiver to a more supportive role.

c. Youth Readiness

For transition planning to succeed, providers, and parents/caregivers must view the youth as the driver in the process and encourage the youth to assume increasing responsibility for his or her own health care to the fullest extent possible. Empowering youth through transitions fosters the development of self-management skills and tools needed for them to gain more control in, and over, their lives.[24] Although this is the case for youth both with and without special health care needs, it is particularly critical for the former, who may require a broader range of considerations during the transition process.[25]

Although this report presents optimal ages for initiating and conducting transition planning, it is never too early to begin conversations among the provider, family/caregivers, and patient about planning for the future. This is especially true for children with special health care needs. For this population, it is likely that similar conversations are occurring in the educational system regarding Individualized Education Plans (IEPs); these various conversations can reinforce and buttress one another.[25] Prioritizing and reinforcing the value of independence and decision-making as part of the transition-planning process not only reinforces such messages on the part of providers, family members/other caregivers, and the broader community but also facilitates the patient's successful transition to adult medical care and active participation in maintaining his or her own health.

3. FRAMING THE ALGORITHM

An algorithm is a finite list of steps connected by various decision-making points that can be taken to move from a known beginning to a predictable end state. As a decision-making tool, an algorithm presents clear-cut questions that, when answered, delineate standardized pathways that lead to the process's next step(s) and a desired outcome. Clinical algorithms have long been popular and effective tools for helping clinicians understand and implement a diagnostic, therapeutic, or management process. Algorithms also provide a logic model for the incorporation of processes of care into electronic health records (EHRs). Algorithms have been included recently in AAP policy documents as strategies to support health care professionals to develop a pattern and practice to address developmental concerns in children from birth through 3 years of age and to engage in early identification of children with autism spectrum disorders.[23,26]

The algorithm contained in this clinical report (Fig 1) specifies the protocol for managing the transition process; assists physicians and other health care professionals to implement the transition process; and provides a transition structure for youth and their families. It is intended for use by clinicians within a medical home setting as a "jumping-off point" for the identification of youth who have reached a point in their lives at which health care transition should be integrated as a routinely recognized part of the office visit. Individual steps along the transition process will vary from one youth to the next depending on individual patient, family/caregiver, health care professional, and community-resource factors. The transition process is best initiated by the time a child is 12 years of age and ideally should occur during a health maintenance or CCM visit. Transfer itself should occur within the 18- to 21-year age range, although it can occur earlier because some internists accept new patients at 15 years of age, particularly if they see other family members as well. Some youth may experience a variety of health care settings as they move from pediatric to adult models of care (eg, while in college or military service), but these settings are not likely to provide a comprehensive medical home. Youth should either remain in their pediatric medical home or be well established in their adult medical home while receiving episodic care in these settings.

a. Explanation of the Algorithm Components

Row 1: Medical Home Interaction

Medical Home Interaction for Patients ≥12 Years of Age

All youth, regardless of whether they have identified special health care needs, should be assessed for transition readiness. Preparation for adult life should be a routinely addressed topic for any health maintenance visit that occurs within the medical home during the adolescent years. The *Bright Futures* initiatives provide content materials on this subject matter.[20] Medical homes can provide appropriate transition services, support, and planning. Transition planning with patients and families must be initiated during an office visit to allow face-to-face communication, because the parties involved may not have previously considered this subject matter. Subsequent medical home transition-planning "interactions" may include, but not be limited to, office visits for health maintenance or acute illness, CCM visits, nursing visits, telephone or e-mail consultations, provision of office policies, and/or record reviews and updates. It is of paramount impor-

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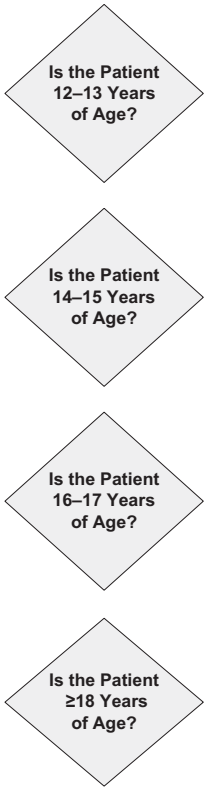
tance that the primary care medical home recognize which youth in the practice have reached the age for transition planning and prompt these families to come in for a visit to initiate the process. Each action step does not require a separate medical home visit, and multiple action steps can be addressed during a visit, although doing so requires a greater investment of time and resources.

Although opinions differ on the age for initiating the transition process, the most appropriate time is early adolescence, when youth become developmentally capable of engaging in activities regarding their personal futures. Therefore, this clinical report recommends initiating the first step in the health care transition-planning process at the age of 12, which allows sufficient time to adequately prepare patients, families, and medical providers before the youth legally becomes an adult at the age of 18. Several clinical studies have found this age to be an appropriate time to initiate the process to most successfully affect the transition's outcome.[27–29]

Children and youth with special health care needs and their families may benefit from discussions regarding adult transitioning that begin earlier than 12 years of age, depending on specific patient circumstances. Expectations for vocation, independent living, guardianship, reproduction, life expectancy, and other topics should be discussed at the earliest possible opportunity with parents and/or other appropriate caregivers if it is determined that the child's transition process will be different from that of children without special health care needs. In addition, some children with chronic medical conditions (eg, asthma or diabetes) may be introduced to developmentally appropriate self-care at ages younger than 12. The timing of these discussions must be individualized.

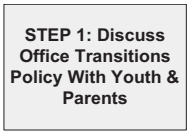
Row 2: Age Ranges

The second row of the algorithm assists health care providers in developing a practice of recognizing the need for transition for all patients 12 years or older. The use of emerging health information technology is likely to aid in this process (eg, through registries and age-related prompts). The age ranges presented in the algorithm are designed to aid the provider in assessing the most appropriate ages for implementing specific stages of transition planning. For most patients, this appropriateness is determined by age, whereas for others, it may be modified on the basis of developmental considerations. The provider's flexibility and judgment are important in this process. Actual transition planning should be initiated at the age of 14. The goal is to identify patients who are either entering or within the 14- to 15-year age range to initiate the development of a patient-specific transition plan at the child's next visit.



Row 3: Action Steps for Specific Age Ranges

Transition is a dynamic and fluid process that includes 4 major action steps. Each of the first 3 action steps (discussion of medical home transition policy, initiation of transition plan, and review/update of the transition plan) lays the foundation for the next. The fourth action step (implementation of an adult care model) prepares the youth and/or caregiver for the transfer to an adult care model. Regardless of the age at which the patient's transition process is initiated, the 4 action steps for transition planning must be accomplished in a linear fashion. For example, if transition is being initiated for a 16-year-old who presents for a health maintenance visit, steps 1 and 2 of the algorithm must be completed before moving to step 3 (the age-appropriate stage for a 16-year-old). As noted, a separate medical home visit is not required for each action step, and multiple action steps can be addressed in a single visit.



In (3a) step 1, the provider shares and discusses the office transition policy with the youth and his or her family or other caregivers. As described previously, every pediatric practice should have a well-defined policy that clearly states the expectations for the health care transition of their adolescent patients to an adult model of care. This policy should be displayed in a location where youth and their caregivers can easily read it (eg, posted in front offices and waiting rooms and described in brochures and on the practice's Web site). The policy should reflect the appropriate level of health literacy, reading and language proficiency, and cultural norms for the population the practice serves. Components of the

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office transition policy include, but are not limited to:

- the expected age of patient transfer to an adult model of health care;
- the patient's responsibilities in preparing for transition;
- the parent, family, and/or caregiver responsibilities in preparing for transition; and
- the medical provider's responsibilities in preparing for transition.

In addition to posting the transitions policy, providers should provide a written copy of the office policy to all patients who are aged 12 or older and their families. Optimally, this policy is provided before a face-to-face encounter between the family/caregivers and the medical provider to allow the patient and family/caregivers sufficient time to become familiar with the policy and prepare any questions they may have before the office visit. Office policies can be given to the transitioning youth and family/caregivers while in the waiting room or be sent to their home before the visit. The delivery and discussion of the office transition policy should be documented in the patient's medical records. Medical home providers should be familiar with each of the transition policy's components to facilitate discussion and respond to questions posed during the office visit. Having a transitions policy that is presented early to the patient and family and other caregivers removes any doubt about the timing of transfer and raises awareness that the medical home will be a valuable support for those who need additional assistance.

For youth without special health care needs, no further transition-specific activities are required until the 14- to 15-year visits. For adolescents with special health care needs, however, the period from 12 to 14 years of age is likely to be spent beginning preparations for transition readiness. For this reason, during the 12- to 13-year visits, the medical home provider must identify those patients who are at risk of having a more complicated transition because of special medical, developmental, social, and/or environmental needs. Some children with particularly complex health care needs may benefit from the early implementation of a formal transition plan before the age of 14.

STEP 2: Ensure Step 1 Is Complete, Then Initiate a Jointly Developed Transition Plan With Youth & Parents

In (3b) step 2, the medical home provider initiates a transition plan that is jointly developed with the youth and his or her parents. Starting at age 14 (or before, for some children with special health care needs, as described previously), a formal transition plan should be initiated for all youth and placed in the medical record for review during future office visits. The written plan should document the youth's current readiness to assume a greater role in self-management of his or her health care, the steps to be conducted to achieve a successful transition, and the transmittal of information to the youth and family/caregivers. It forms the basis for records to be provided to the receiving provider and youth on the transfer of care between the ages of 18 and 21. Implementation and review of the transition plan can be an important measurable quality-improvement effort on the part of the medical home.

The starting point for this step is the recognition of patient capabilities and delineation of responsibilities between patient, family and other caregivers, and medical providers for overall patient care. Practices should select a readiness-assessment tool to use that can be modified for specific patient situations. Readiness tools reveal areas of both strength and weakness on which patient education can be focused to accomplish future goals in self-management. Regardless of the tool chosen, it should contain specific minimum components that provide an accurate, point-in-time assessment of the individual patient's ability to transition successfully. (These components are described below. Many readiness-assessment tools and skills checklists exist for conducting this assessment; some are listed in "Resources.")

No matter what tool is used to assess and document readiness, providers should interview family members or other caregivers and the youth independently of one another to identify needs and assess intentions and motivations for the patient's independence. The identification of special health care needs (medical or otherwise) requires the medical home to be proactive in facilitating relationships between the youth and appropriate community and/or state resources.

STEP 3: Ensure Steps 1 & 2 Are Complete, Then Review & Update Transitions Plan & Prepare for Adult Care

In (3c) step 3, the medical home provider reviews and updates the transition plan and works with the patient to engage in the transition process. The transition plan documentation should be reviewed on a regular basis to promote recognition by the patient, the family/caregivers, and the provider of successes and/or deficits in readiness preparation. Medical providers and caregivers can reprioritize the readiness goals with respect to changes in the youth's medical status and/or concerns on the part of the caregivers. Although the number of times this review occurs depends on the frequency of the patient's visits to the medical home, it should be conducted at least

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annually. Focused efforts and intensified communication (among the patient, family members and other caregivers, and providers) may uncover systemic roadblocks or deficiencies in the patient's abilities to achieve previous expectations.

If there has been a failure to achieve transition-readiness goals, a reevaluation of the existing plan is warranted; it may be necessary to increase the frequency of medical home interventions or visits. Because 16- to 17-year-olds are significantly closer to the age of expected transfer of care to an adult model, accomplishing transition goals may not be feasible within the annual health maintenance schedule. Readiness plans will require revision on the basis of the outcome of such communication.

Successful transition requires the identification of an adult care medical home, and completion of this task is one of the most important for pediatric providers. The patient and/or family (and other caregivers) may need assistance identifying available and qualified adult care providers; when they select an adult provider, it is the pediatric medical home's responsibility to ensure appropriate communication of any and all medical needs to the receiving provider. In the final year before transfer from the pediatric medical home, the youth and family/caregivers might benefit from a visit with the potential adult provider(s) to explore the potential of a long-term relationship. Pediatric care occurring within a family medicine practice obviates the need for such a visit but not the need for preparation for an adult model of care.

STEP 4: Ensure Steps 1, 2, & 3 Are Complete, Then Implement Adult Care Model

In (3d) step 4, the medical home provider implements an adult care model or affects the transfer to an adult medical home provider. After documented completion of the readiness goals in the individual youth's transition plan, the pediatric provider's role is to facilitate transfer of care to an adult medical home. For young adults with complex health care issues, direct communication between pediatric and adult providers is essential, because adult medical personnel may be unfamiliar with certain pediatric conditions.[17] For youth with complex needs, families are almost always a significant part of this conversation, because they are likely to be highly involved in not only caring for the youth but also arranging for, and supervising, others who provide care. The provider, youth, and family must jointly prepare a portable medical summary and, for children with special health care needs, a care plan, which should be delivered to the patient (or his or her legal guardian) and to the receiving provider. EHRs should also be provided to the adult provider. Medication reconciliation should be performed by the pediatric medical home before the record is transferred and by the receiving adult medical home when the record is received. (The components of this summary are described in "Implementing the Algorithm.")

Health care transition does not necessarily end with transfer. Some patients and/or caregivers may need additional support from the adult medical home to complete specific transition tasks. Providing this support through care coordination and consultation within the adult medical home optimizes the patient's self-management skills. In addition, the pediatric provider should make himself or herself available to the adult provider as a resource for any needed information or assistance during the immediate posttransfer period.

Row 4: Determination of Special Needs

Does Patient Have Special Health Care Needs?

The transition process may be simpler for youth without disabilities or chronic health conditions compared with those with special health care needs. If the youth has no special health care needs, the provider's primary task is to ensure that all age-appropriate transition issues are addressed and that a smooth transfer to an adult model of care occurs. For the youth with special health care needs, the transition process should be initiated at the age of 12 and may necessitate specific CCM activities (these components are described below). The MCHB definition encompasses a wide variety of conditions and range of severities, including children with developmental disabilities and chronic illnesses as well as those with mental health and behavioral disorders.[21] The development of patient registries to aid in the identification of these children is a core component of CCM within the medical home model. An important feature of such planning is the recognition that many tasks that lead to patient self-management are beyond the capability of young adults whose medical conditions include cognitive challenges. Transition goals must be individualized to account for such variations.

Row 5: CCM and Follow-up

Incorporate Transition Planning in Chronic Condition Management

To the extent possible, basic transition planning and preparation for an adult

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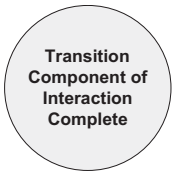
health care model should be the same for children and youth with and without special health care needs. For many children and youth with chronic medical, developmental, and/or behavioral conditions, however, an expanded process of transition planning is necessary to address the exchange of more complex health information, competencies for self-care, and the transfer of specialty care from pediatric to adult medical subspecialists. In addition, broader transitional issues related to health insurance, entitlements, guardianship, and eligibility for adult community-based services must be addressed also. In a medical home, some youth with special health care needs will have a written care plan as part of the medical record that can serve as a script for care coordination and care planning. At the age of 14, this written care plan should begin to include a section titled "transition plan"; this transition section should be developed steadily as the youth approaches the age of 18 and beyond. (Transition planning in CCM is more described fully below.)

Regardless of whether the child has special health care needs, providers should ensure that age-appropriate transition issues have been addressed at every medical home visit and that the process is on track. Use of appropriate transition-planning tools and readiness checklists will facilitate the provider's ability to answer this question. The act of "addressing" transition issues is not synonymous with the successful completion of the process, however. Identification of items in need of attention, and the formulation of plans to accomplish them, may be sufficient to complete this action step. If patients have fallen behind the transition-planning schedule, providers are likely to need to schedule a special visit to complete all of the tasks related to transition planning.

Follow-up interactions may take one of several forms. Focused tasks that involve little detail or complexity can be addressed by staff such as the medical home care coordinator or medical provider via telephone communication or electronic media (eg, secure e-mail). Larger or more complex issues may necessitate 1 or more face-to-face office visits, which should not be relegated to the next periodic health maintenance visit.

Row 6: Interaction Complete



This point does not mean that the office visit is complete or that the provider does not continue to provide care, merely that the part of the process of providing care that centers around transition planning has been completed for this specific office visit or interaction.

4. IMPLEMENTING THE ALGORITHM

Every youth who reaches the age of transition from a pediatric medical home or becomes a legal adult within his or her current medical home needs to have a basic transition plan developed through collaboration among the youth, family, and provider. Those with special health care needs require additional components specifically to address their chronic care management (see "Integrating Transition Planning Into CCM for Children and Youth With Special Health Care Needs").

a. Transition Plan Components for Every Child and Youth

There are 4 recommended components for a transition plan, each of which can be augmented by the use of specific tools to facilitate the work of the provider, youth, and family.

1. *Assess* for transition readiness. The provider, family, and youth begin by articulating realistic goals for transition and identifying new skills that will be needed by the patient to meet those goals successfully. Although it is not the main focus of the medical home, the assessment should be "person-centered" and include identification of other areas of readiness for transition into the adult world in general, including education/vocation, independent living, and patient awareness of medical needs and age-appropriate preventive care, as outlined by resources such as *Bright Futures*.[18] Numerous tools are available in the form of "readiness checklists" that allow providers to obtain a baseline idea of the current capacity of the youth, family and other caregivers, and providers to successfully achieve the outlined goals. Transition progress should be measured through periodic reassessment using the same checklists at each visit (see "Resources" for selected transition-readiness materials).
2. *Plan* a dynamic and longitudinal process for accomplishing realistic goals. The first step of transition planning is the establishment of goals that allow the youth to achieve as seamless a transition as possible. A formal, written transition plan that outlines specific actions that are necessary to meet the stated goals should be part of the patients' medical record by the

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age of 14. The written transition plan should account for cultural, developmental, organizational, and contingency-related concerns. In general, categories recommended to be incorporated into the transition plan include the plan's main goal(s), identification of who within the medical home will be responsible for overseeing and/or coordinating the plan, the time line for accomplishing stated goals, the skills required by the youth to achieve maximum self-management, the families' or other caregivers' role, and an articulation of proposed financing of the youth's adult health care (see "Resources" for selected transition-planning tools).

3. *Implement* the plan through education of all involved parties and empowerment of the youth in areas of self-care. After the transition plan has been outlined and goals have been established, specific activities to ensure that the youth acquires needed skills should begin. Examples of these goals include the ability to schedule one's own medical appointments, obtain medications, have a one-on-one dialogue with a medical provider, and be familiar with one's medical history and any needed medications. Ongoing discussion of the transition plan at all health care visits is a key step in accomplishing transition goals. This should be a dynamic process that begins gradually and is continually assessed at regular intervals. The timing of these reassessments depends on the capacity of the youth and his or her family and other caregivers as well as the amount of time remaining until the anticipated transfer of care to the adult medical home. The transition-readiness checklists used during the initial assessment to establish goals (outlined previously) are the tools of choice for documenting successful accomplishment of specific goals and tasks. It is highly recommended that a medical home use the same checklists throughout the entire transition process for an individual patient to provide continuity over time and assist youth, families, and providers to stay "on track" regarding specific goals that have yet to be accomplished.

   Throughout this process, the provider should continually strengthen the partnership with the patient and family members and other caregivers by engaging in active dialogue and information-sharing to empower the youth to take on new roles, as appropriate. It is important to recognize that, at the age of maturity, the youth becomes a legal adult (except when guardianship by another person has been obtained). As a result of confidentiality laws, the youth should be seen alone unless other arrangements have been legally made. One to 2 years before the anticipated transfer of medical care, the pediatric provider should assist the youth and/or family/caregivers to identify potential adult practices, prepare the appropriate documentation for transition, and suggest that the youth interview the adult practice before making a final transfer.

4. *Document* progress to enable ongoing reassessment and movement of medical information to the receiving (adult care) provider. Many excellent tools for documenting the transition process exist, including some that can be used within an EHR system and others that are paper-based. For example, providers might place a transition front sheet on the patient's chart or use a "dashboard" tool in the patient's EHR at the age of 12. Both of these methods work well in flagging important actions that have occurred and/or need to be scheduled as part of the transition process. Regardless of the specific tool used, it should provide a flexible method for assessing the youth's readiness for transition and progress made toward that goal. Gathering relevant information to document the patient's transition progress is of paramount importance as the anticipated transfer date approaches. It is well documented that a common barrier to adult medical providers' acceptance of transitioning youth is a lack of accompanying medical documentation.[16] It is critical that medical documentation be portable and include 3 components: (1) the transition plan (see above); (2) longitudinal readiness checklists (see above), which demonstrate both successes and deficits in self-management skills; and (3) a portable medical summary. The portable medical summary contains basic medical and social data to give adult medical providers the information necessary to begin assuming care for the patient. All youth receive this portable medical summary, because the data it contains are essential topics and elements that are critical to the transition summary. Although the categories of the medical summary are appropriate for all chronic health conditions, specific information should be tailored to the patient's conditions.

b. Integrating Transition Planning Into CCM for Children and Youth With Special Health Care Needs

Transition planning applies to all children and youth and should follow the steps defined in the algorithm. The presence of chronic health conditions and/or developmental disabilities (ie,

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children or youth with special health care needs) imposes specific primary care requirements on the family-centered medical home characterized as CCM. Effective CCM, in turn, demands additional considerations related to transition planning. CCM involves an explicit, planned process of coordinated, proactive care aimed at achieving the best possible clinical and functional outcomes for the individual patient and for the population of patients with chronic conditions. While following the general sequence and timing of the transition algorithm, transition planning for children or youth with special health care needs will usually be incorporated into the broader CCM process. Early in the transition-planning process, it will be important to determine whether the youth is likely to be a completely independent decision-maker as an adult or require decision-making support from a third-party proxy such as through guardianship or power of attorney. Even with these considerations in mind, it is important to plan with the youth and family/caregivers to achieve the maximum possible participation of the youth in the transition-planning process.

1. Registry. The family-centered medical home CCM process may include a registry of the practice's patients with special health care needs. The registry should be searchable on the basis of patient age so that youth who are ready for each stage of the transition process (see algorithm) can be identified. The registry might also include fields indicating which steps in the transition process are due for completion, have been completed, or are past due for completion. Additional fields unique to the transition of children or youth with special health care needs might include "discussed guardianship," "identified adult subspecialists," etc.
2. Care Plan. Some children or youth with special health care needs will have an action-oriented care plan for tracking current problems and health-related needs including what action is needed, who will be responsible, and by when the action should have occurred. When a child or youth with special health care needs enters the age group covered in the transition algorithm, the action-oriented care plan should begin to contain a transition section that will become the youth's transition plan. The incorporation of the transition plan into the general action-oriented care plan will ensure integration of transition planning with other health-related actions.
3. Care Coordination. Care coordination is one of the foundations of the family-centered medical home and assumes special importance for children or youth with special health care needs who utilize the health care system frequently and who may have multiple health care and other service providers. Those who coordinate health care for the child or youth with special health care needs will need to take into consideration the youth's transition plan and the current stage of the transition-planning process. Care coordination may be instrumental in supporting the transfer of care from various pediatric medical subspecialists to their adult specialty counterparts.
4. CCM Visits. The family-centered medical home provides periodic CCM visits that may occur in addition to health maintenance and acute illness management visits to monitor the status of patients with chronic conditions and implement/update their care plans. These CCM visits would provide the occasions for transition education and planning.
5. Comanagement. Explicit comanagement between primary care physicians and medical subspecialists ensures communication and prevents both omissions and redundancies of care. It explicitly identifies the respective roles of the primary care medical home and the medical subspecialists in a manner that is clear to each provider and the youth and family and other caregivers. The locus of management may shift from time to time between primary care and specialty care depending on the youth's age and the complexity and acuity of specific health problems. Comanagement with medical subspecialists assumes particular importance for transition planning, because it provides the framework in which to plan for and implement the transfer of care from pediatric subspecialists to adult medical subspecialists and surgical specialists. Comanagement may also be the context for a dialogue of explicit communications between the youth's medical home and the future adult medical home provider. Comanagement planning with respect to transition planning should include the timing and process for specific transfers of care in each relevant specialty area. In some cases, the plan may be to retain a pediatric subspecialist into adulthood because of the absence of appropriately qualified adult medical subspecialists.

It should be noted that some diagnosis-specific programs, including clinics for hemophilia and cystic fibrosis, have established strong programs to guide subspecialty transfer. The National Hemophilia Foundation established a nationwide network of

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hemophilia diagnostic and treatment centers and, in 2003, adopted transition guidelines that provide age-related recommendations. These models and transition guidelines acknowledge that there are continuing areas for improvement such as addressing preventive health needs or promoting the adult model of decision-making by young adult patients.[30,31]

i. Components of the Transition Plan for Youth With Special Health Care Needs: Necessary Information for the Receiving Provider, Patient, and Family Members/Caregivers

In addition to the items in the transition plan for all youth (described previously), additional components should be included in transition plans and records for youth with disabilities and/or special health care needs. All transition plans should be tailored to the individual patient and his or her needs.

Additional data elements that are likely to be included in the transfer documentation for youth with special health care needs include baseline functional and neurologic status; the patient's cognitive status, including formal test results and date of administration, when possible; condition-specific emergency treatment plans and contacts; and the patient's health education history and assessment of his or her understanding regarding health conditions, treatments, and prognosis with particular attention to entry into adult life, including procreation potential and genetic information.

Information about advance directives should include an identification of the decision-maker proxy or guardian and any history of advance-directive planning. For patients with communication impairments, the transition documentation should include the patient's communication preferences and anticipated needs for accommodations in both communication and clinical care (ie, use of sign language interpreter, augmentative communication device, etc).

ii. Components of the Transition Plan for Youth With Special Health Care Needs: Assessment and Documentation of Readiness

As part of the transition-planning process, a member of the medical home team should regularly assess the patient and his or her family and other caregivers on progress toward achieving transition readiness and preparation for adult life. Interventions to address individual difficulties and/or provide extra resources should be conducted during visits. Education and empowerment techniques should be used to ensure that development of needed skills is embraced by the patient and families and continues to occur. Providers must ensure that they document both the patient's and family's progress toward successfully completing the plan's components as well as any plan revisions. A formal method should be used to document the stepwise completion of developmentally appropriate tasks required to prepare the transitioning patient for adult life. Flow sheets, registry reminders, and planned visit templates for specific ages are all possible means to do so. In addition, documentation is particularly important in certain specific areas.

Insurance Coverage

The 2010 Patient Protection and Affordable Care Act (PPACA) health care reform legislation will affect coverage, access to care, and care coordination in the short-term and/or long-term. Specific provisions of the PPACA expand children's and youth's access to coverage and ongoing care, including changes that permit children to remain on their parent's insurance until the age of 26; eliminate insurers' ability to exclude coverage on the basis of preexisting conditions; improve coverage portability; create a high-risk pool insurance for people who cannot access coverage through other sources; enhance Medicaid payment to primary care physicians; and mandate that nearly all people (including young adults) have coverage. Although these changes are likely to prove beneficial, it is likely that parents, caregivers, and transitioning youth alike will need assistance to understand this complex legislation and its impact on their lives and the transition process. In addition, PPACA provisions are to be implemented over time, and youth must be encouraged to proactively plan to avoid suffering substantial coverage gaps and/or delays in coverage because of "preexisting conditions" until 2014, when this practice is prohibited under PPACA. In addition, age eligibility and coverage requirements may vary for programs such as Title V, Medicaid, Supplemental Security Income (SSI), and Social Security Disability Income (SSDI). Youth with chronic conditions should be encouraged to evaluate future employment options that are most likely to offer insurance coverage for high-risk people (ie, employers who participate in large group plans and, thereby, spread out risk). Parental employment-based coverage limitations also vary widely; although a few plans cover adults with disabilities who are dependents of their parents, they are the exception. Because of the critical nature of insurance coverage for people with special health care needs, it is essential that providers discuss insurance issues with these patients and document plans to ensure continued coverage.

Self-Advocacy

Critical topic areas for the empowerment of youth with special health care needs include self-advocacy and

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making plans about decision-making status, educational and/or employment opportunities, living arrangements, and community-inclusive opportunities. It is critical to encourage families to initiate training and decision-making opportunities for children with special health care needs at a young age. Families should receive assistance from experts in self-advocacy when considering the range of potential support, which may include personal informal advocates, power of attorney, and limited-to-full guardianship. Important resources include organizations, such as Family Voices; local chapters of The Arc; and lawyers who are experienced in disability issues. Because of the importance of self-advocacy for youth with special health care needs, it is essential that providers initiate conversations about decision-making and begin to plan advocacy support for these youth far in advance of the age of majority.

Legal Issues

The assessment of the patient's potential capacity to consent occurs as part of the ongoing CCM process. Providers should suggest goals and action steps that help youth achieve their fullest potential and participate as much as possible in assent and consent processes during their clinical care. It is critical that youth and family members and other caregivers alike understand the significant health system changes associated with the age of majority, including support-service or program-eligibility changes, selective service registration requirements, consent and confidentiality provisions, and guardianship issues. Youth and family members/caregivers need to think about how health care decisions will be made once the youth turns 18. Because of the particular importance of legal issues for youth with special health care needs, it is essential that providers ensure that both the patients and family members understand and are prepared for legal changes associated with adulthood. In addition, problems can arise when a youth is incapacitated and unable to direct his or her own care. Preparing a health care proxy or power of attorney for the young adult will avert such a situation.

Health Education

People with chronic conditions should receive periodic, updated health education about their condition. Necessary information includes an understanding of the patient's specific condition; typical disease process and prognosis; current treatment and treatment options; medication knowledge; self-assessment; and self-care issues, especially in defining emergent situations and responses. Particular attention should be paid to issues of puberty that may not have presented earlier, such as sexual expression, reproductive issues, and genetic transmission. Because of the importance of the patient's understanding his or her own condition, it is essential for providers to document that this information has been provided to, and understood by, the patient.

Caregiver's Issues

Assessment of family/caregiver adaptation is another component of the transition-readiness assessment for families of children and youth with chronic conditions. Attention should be paid to coping on the part of the youth, his or her parents and siblings, and any other appropriate family members and other caregivers. Parents and caregivers must adapt to the transition of authority from parent to youth that occurs when the youth has the capacity to accept the transfer and may experience grief if the child lacks the capacity to assume independent decision-making. For this reason, providers must be ready to help parents and caregivers cope with the life changes associated with chronic conditions as well as with transfer planning. Because these situations can be stressful for the youth and family members/caregivers alike, it is essential that providers assess patients' coping mechanisms and provide referrals for additional care, as appropriate.

5. ADULT MEDICAL HOME (RECEIVING PROVIDER): ROLES AND RESPONSIBILITIES

The transition of a young adult will make it necessary to identify an adult practice that is prepared to accept the patient and provide the full range of care and care coordination in an appropriate, patient-centered care model. Most young adults are healthy and require only the continuation of health maintenance and promotion and the availability of an adult medical home when acute illnesses arise. Yet, even the population of young adults without special health care needs includes those with adolescent-type risky behaviors, mental health issues, and reproductive health needs that require enhanced attention. Young adults with disabilities and chronic medical conditions are more vulnerable to failures in the transition of health care services and require more attention from providers and the health care system. Fundamentally, clinical hurdles and process hurdles present major challenges for a successful move to adult-oriented care for young adults with special health care needs.

The transition of a young adult necessitates the identification of an adult practice that is prepared to accept the patient and provide the full range of care and care coordination in an appropriate patient-centered care model. Shortages in the adult medical home workforce may limit future ca-

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pacity to do so. Thus, clinical hurdles largely encompass deficits in education and/or experience of some adult providers to effectively care for this diverse patient population, as well as financial disincentives that limit access to adult-oriented care. The authors of several recent articles have explored the perspective of adult providers participating in the medical transition of young adults with special health care needs. Okumura et al[15] found that, when adult medical care providers were exposed to the process of transitioning young adults in the context of their residency training experiences, they were much more likely to incorporate it into their practices after residency. Anecdotally, however, these residency training experiences are not common, and many practicing physicians have learned "on the job" to manage patients with complex needs. A recent survey of internists' needs when accepting a transitioning youth revealed that education in congenital and childhood-onset conditions was critical.[17] In addition, the respondents cited the need for identified medical subspecialists to help with management decisions. Although adult medical providers have the role of assuming the care and management of these youth, they should not be expected to do so without supports that are more readily available to pediatric providers.

Caring for young adults with special health care needs may represent a challenge that some adult primary care practices are currently not prepared to meet. Further work is needed to characterize, demonstrate, and teach an adult model of care that is responsive to the particular needs of all young adults and sensitive to the specific challenges associated with providing high-quality care to young adults with specific chronic conditions (eg, autism, cerebral palsy, intellectual disability, sickle cell disease). Ideally, the health care payment system would encourage early and ongoing professional relationships with pediatric providers in anticipation of transitions and also support comanagement with pediatric primary care and medical subspecialty providers while the patient is becoming established with the adult practice. At some point, the responsibility for the transitioning young adult will become that of the adult provider, at which time, the adult provider and his or her clinical team should assume a key role in supporting the young adult and his or her family and other caregivers in finding a new balance in the adult medical setting. The transitioning youth's developmental and functional abilities may influence the transition's success. The continued involvement of the family/caregivers should be expected and encouraged during this transition period. In addition, working with the family and other caregivers and other supports to ensure adequate health care insurance and financing for these youth is a major goal of transition.

Second, process hurdles include challenges in the communication of appropriate medical records; community resources; preparation of the young adult and his or her family/caregivers to integrate into an adult-focused medical system; and issues related to payment. Adult providers should not expect a "handoff" from pediatric practices but, rather, a "handshake." Establishing collegial relationships between pediatric and adult medical providers is important for facilitating ongoing access to medical care for patients in transition. Although every transition is different, the best transitions include several core elements. Receivers (providers to whom the youth transitions for care) may reasonably expect that, as the adult medical home team, they will be provided with concise and accurate medical information about the youth and his or her condition, as described previously. In addition, receivers should ensure that:

- the responsible party for medical decision-making has been clearly identified;
- unambiguous adult consent and confidentiality policies have been explained to the patient and his or her family and other caregivers;
- communication has occurred about how the practice operates for issues such as paperwork and medication refills; and
- access to the practice for routine and after-hours care has been discussed with the patient and his or her family and other caregivers.

Although many young adult patients will transition to adult practices from pediatric-based practices, the unique relationship that many family physicians have with their patients allows for ongoing care throughout the life span. Although transfer of care many not occur in these situations, it is likely that young adults with special health care needs have pediatric subspecialists who may wish to facilitate transfer to their adult counterparts. The family physician has the special responsibility to be aware of these needs and, in some situations, to potentially play the role of both the "sender" and "receiver."

Certainly, successful transition is a test of the degree to which a practice operates within the ideals encompassed in the medical home model of care. A team approach to the challenges of transition is necessary for facilitating the level of care for which adult providers strive. Inclusion of local public health and community-based resources should be considered whenever possible to ensure that the medical home approach is followed,

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particularly for vulnerable patient populations with special health care needs.

Payment for Health Care Transition Work

The steps involved in the health care transition algorithm are intended to be part of existing office visits using well-established billing codes. For youth without special health care needs, transition preparation and planning would be incorporated into regularly scheduled health maintenance visits and billed as such (Current Procedural Terminology [CPT] codes 99394 and 99395). For youth with special health care needs who have sufficient complexity to justify periodic CCM visits in addition to health maintenance visits, health care transition preparation and planning are intended to occur during a CCM visit billed as a prolonged encounter with an established patient (CPT codes 99214 or 99215). Such visits can be documented as involving counseling for more than 50% of the visit. Youth with highly complex needs may require a CCM visit in which the counseling provided is devoted entirely to transition, but these visits are still reimbursable when using the prolonged-encounter codes and the counseling rule. Activity outside of office encounters involved in the management of a youth's transition plan (whether it stands alone or is incorporated into a more general care plan for a chronic condition) constitutes "care plan oversight." Such work may involve phone calls to prospective adult primary care physicians or medical subspecialists, conversations with the youth and family regarding transition plans, or communication with community agencies integral to the transition process. These activities can be billed by using care plan oversight CPT codes 99374 (15–29 minutes) and 99375 (≥30 minutes) through which the physician can bill monthly for the cumulative time spent on care (or transition) plan oversight. Similar coding and billing options may be exercised after the transfer of care from a pediatric medical home to an adult medical home.

6. CLINICAL GUIDANCE AND FUTURE SUGGESTIONS

This report attempts to address the need for guidance to aid practitioners' implementation of youth transition planning into practice. Yet, transitions cannot occur in a vacuum. Systemic barriers that have been reported as factors that hamper clinicians from implementing needed changes include lack of training and payment for transition activities, receivers to accept these patients, research to identify best practices, and advocacy to advance the research results. Increased training on the critical skill of transitioning can be integrated into an adolescent medicine rotation in internal medicine and into the adolescent medicine and continuity clinic rotations for pediatric residents. Med-peds, pediatrics, and family medicine residencies may provide significant training opportunities in this area. Dually boarded med-ped physicians would seem ideally equipped to care for transitioning adolescents and young adults and to assist in the training of other primary care generalist physicians regarding care over this age range. Unfortunately, the med-peds workforce remains too small and is not likely to grow sufficiently to affect the health care transition of most youth and young adults.

Graduate medical education programs may also provide a forum for pediatric and adult providers to build and maintain relationships that are needed to enhance collaboration and improve communication, ultimately facilitating comanagement of complex conditions. Payment is a crucial element in the promotion of transition planning. Incorporating transition planning into CCM is a process that costs time and money and should be included in conversations about care coordination and payment. Further research is required to define best practices, clinical pathways, and cost-effectiveness for transition planning. Quality-improvement science may provide additional methodologies to inform the understanding of potential strategies. Once best practices are identified, advocacy and education efforts will need to be directed toward several areas including:

- enhanced payment for transition services;
- case-finding of those in need of transition services who are not receiving them;
- insurance coverage for patients in need of transition planning;
- standards of care and credentialing of providers;
- training for primary care physicians and medical subspecialists to promote transitions within the medical home; and
- promotion of training and clinical learning experience on transition and transfer of youth and young adults (both with and without special needs) for trainees in all medical fields.

7. CONCLUSION

A well-timed, well-planned, and well-executed transition from child- to adult-oriented health care, ideally occurring between the ages of 18 and 21, enables youth to optimize their ability to assume adult roles and activities. For this reason, transition planning should be a standard part of providing care for all youth and young adults, and every patient should have an individualized transition plan regardless of his or her specific health care

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needs. The AAP, American Academy of Family Physicians, and American College of Physicians recognize that providers need assistance to accomplish this goal. Education of practicing and resident physicians in training is essential for the integration of the concepts of the patient- and family-centered medical home, the principles of transition of care, and the processes for successful transfer of care. Therefore, this clinical report provides a consensus on activities to support the practice-based implementation of transition planning for youth with and without special health care needs. It describes a series of activities designed to ensure that uninterrupted, high-quality, and developmentally appropriate health care services are available to patients moving from adolescence to adulthood. The clinical report provides a clear time line, beginning at 12 years of age, to assist providers in implementing the 4 specific activities in transition: discussing the medical home transition policy; initiating a transition plan; reviewing/updating the transition plan; and implementing an adult care model. It also includes an algorithm that specifies the protocol for managing the transition process, helps providers implement the transition process, and provides a transition structure for patients and their families. The algorithm includes a branch with expanded, generic guidelines for transitioning youth with special health care needs who require CCM. Primary care providers and medical subspecialists are encouraged to make this process specific for their own and their patients' needs.

8. RESOURCES

a. General Resources

- National Health Care Transition Center (www.gottransition.org).
- Family Voices, Inc (www.familyvoices.org).
- Family-to-Family Health Information & Education Center (www.bridges4kids.org/f2f).
- Kids as Self Advocates (KASA) (www.fvkasa.org).
- National Alliance to Advance Adolescent Health (www.thenationalalliance.org).

b. Transition Care Plans

- AAP/National Center for Medical Home Implementation (www.medicalhomeinfo.org/how/care_delivery/transitions.aspx).
- British Columbia Ministry of Children and Family Development, "Transition Planning for Youth With Special Needs" (www.mcf.gov.bc.ca/spec_needs/pdf/support_guide.pdf).
- University of Washington, Adolescent Health Transition Project (http://depts.washington.edu/healthtr).

c. Transition Assessment and Evaluation Tools

- AAP/National Center for Medical Home Implementation (www.medicalhomeinfo.org/health/trans.html).
- JaxHATS, evaluation tools for youth and caregivers and training materials for medical providers (www.jaxhats.ufl.edu/docs).
- Texas Children's Hospital transition template (http://leah.mchtraining.net/bcm/resources/tracs).
- Carolina Health and Transition Project (CHAT) (www.mahec.net/quality/chat.aspx?a=10).
- University of Washington, Adolescent Health Transition Project (http://depts.washington.edu/healthtr).
- Wisconsin Community of Practice on Transition (www.waisman.wisc.edu/wrc/pdf/pubs/THCL.pdf).

d. Portable Medical Summaries

- AAP/National Center for Medical Home Implementation (www.medicalhomeinfo.org/how/care_delivery/transitions.aspx).
- National Diabetes Education Program (www.YourDiabetesInfo.org or www.ndep.nih.gov).
- Sick Kids (www.sickkids.ca/good2go).
- University of Washington, Adolescent Health Transition Project, medical summary (http://depts.washington.edu/healthtr/medsum/portable_medsum.pdf).

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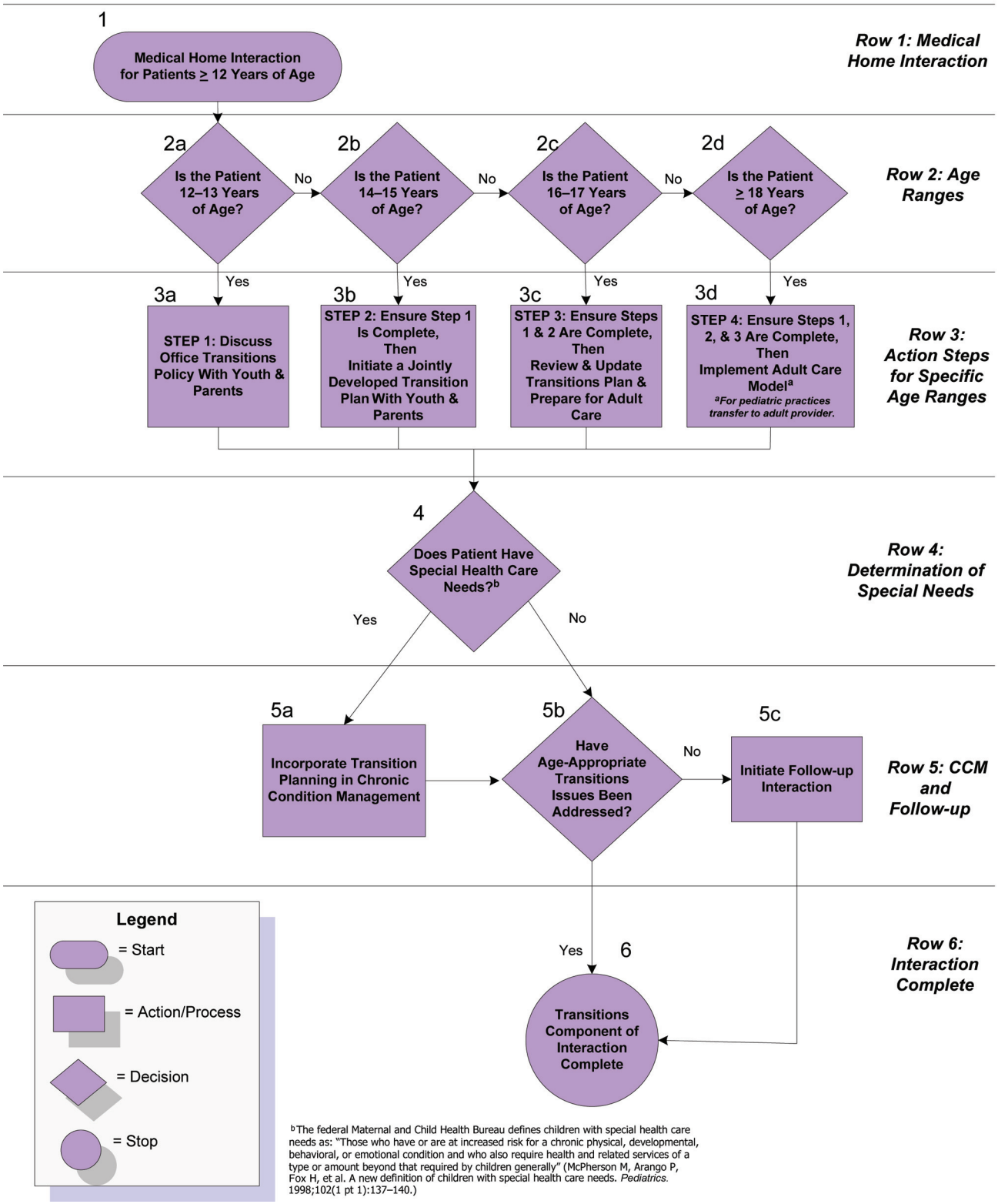
Health Care Transition Planning Algorithm for All Youth and Young Adults Within a Medical Home Interaction



[b]The federal Maternal and Child Health Bureau defines children with special health care needs as: "Those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally" (McPherson M, Arango P, Fox H, et al. A new definition of children with special health care needs. *Pediatrics.* 1998;102(1 pt 1):137–140.)

APPENDIX 1

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Medical Home Interaction for Patients ≥ 12 Years of Age

1. Initiate first step in the health care transition planning process at age 12.

Is the Patient 12–13 Years of Age? | **Is the Patient 14–15 Years of Age?** | **Is the Patient 16–17 Years of Age?** | **Is the Patient ≥ 18 Years of Age?**

2a, 2b, 2c, 2d. Age Ranges. By age 12, conduct surveillance to assess any special health care needs. Start actual transition planning by age 14. By ages 16-17, transition planning should be well established. At age 18, initiate an adult model of care for most youth, even if there is no transfer of care. If transition planning does not occur on the schedule described by the algorithm, a concentrated effort is required (eg, special visits) to successfully complete the process.

3a. Every practice should have a written transition policy that is prominently displayed and discussed with youth and families. The policy should explicitly state the practice's expectations and care process for the health care transition of their adolescent patients to an adult model of care.

STEP 1: Discuss Office Transitions Policy with Youth & Parents

STEP 2: Ensure Step 1 Is Complete Then Initiate a Jointly Developed Transition Plan With Youth & Parents

3b. The practice should utilize a standard transition plan that can be adapted for each patient's needs. This tool should include components to obtain an accurate assessment of the patient's ability to successfully transition. Providers should interview youth and family members to identify needs and to assess the intentions and motivations for youth independence.

3c. Transitions plans must be reviewed regularly and updated as necessary. The provider must also perform surveillance for changes in the youth's medical status and address youth and family concerns that may warrant changes in transition goals. Failure to achieve transition readiness goals warrants reevaluation of the existing plan, and increased frequency of medical home interventions/visits. A "pretransfer" visit to the adult medical home could be conducted during the year before the transfer.

STEP 3: Ensure Steps 1 & 2 Are Complete, Then Review & Update Transitions Plan & Prepare for Adult Care

STEP 4: Ensure Steps 1, 2, & 3 Are Complete, Then Implement Adult Care Model[a]
[a]For pediatric practices transfer to adult provider

3d. Transition to an adult model of care occurs appropriate for youth's developmental level. This is followed as appropriate by transfer to an adult medical home. Complete medical records should be delivered to the adult provider, along with a portable summary, which is also provided to the patient or guardian. For children and youth with special health care needs, direct communication between pediatric and adult providers is essential, as adult medical personnel may be unfamiliar with certain pediatric conditions.

4. Transition planning for children and youth with special health care needs should include specific chronic condition management (CCM) activities such as: use of registries; care plans; care coordination; CCM office visits; and comanagement with medical subspecialists. Transition goals must be individualized to account for variations in the complexity of a youth's condition and in the youth's intellectual ability and guardianship status.

Does Patient Have Special Health Care Needs?[b]

Incorporate Transition Planning in Chronic Condition Management

5a. Youth with special health care needs require an expanded transition planning process. Transition planning in CCM includes addressing the exchange of complex health information; competencies for self-care; transfers of specialty care; and issues related to insurance, entitlements, guardianship, and eligibility for adult services. In a medical home, such youth may have a written care plan as part of the medical record. At age 14, this plan should include a section titled "transition plan," which should be expanded and developed as the youth approaches age 18 and beyond.

5b. Use of transition planning tools and readiness checklists facilitate the provider's ability to ensure that all age-appropriate transition issues have been addressed. Each action step must be completed in order, even if this means the provider has to schedule specific visits to initiate and complete steps missed earlier in the process in order to catch up before the next visit.

Have Age-Appropriate Transitions Issues Been Addressed?

Initiate Follow-up Interaction

5c. Focused tasks involving little detail or complexity can be addressed by the medical home care coordinator, medical provider, or other appropriate staff through telephone or electronic media. More complex issues may necessitate face-to-face office visits.

6. The provider is finished with the transition tasks for that specific interaction or visit; transition planning is an ongoing activity that occurs at every interaction.

Transitions Component of Interaction Complete

APPENDIX 1 CONTINUED

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Supporting the Health Care Transition From Adolescence to Adulthood in the Medical Home

American Academy of Pediatrics, American Academy of Family Physicians, and American College of Physicians, Transitions Clinical Report Authoring Group

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