Facilitating the Transition from Pediatric-Oriented to Adult-Oriented Primary Care

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Defining Pediatric to Adult Transition

"Transition is the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented health care systems" [1]. It represents not only the passage from one developmental stage to another (dependence to independence), but also represents the passage from one type of care (pediatric/family-centered care to adult/patient-centered care) and often the change to a different health care setting. Although all youth transit to adult-focused care, usually between the ages of 18 and 21, youth with special health care needs (YSHCN) typically require an expanded process of transition planning to address the exchange of more complex health information, competencies for

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self-care, transfer of specialty care, and issues related to public program eligibility, decisionmaking supports, and coordination with community services.

Transition from pediatric to adult health care refers to a set of actions designed to ensure continuity of care between pediatric and adult health care settings and improve health literacy so that youth and young adults understand and manage their own health needs and navigate the health care system. Transition takes place over time, beginning in early adolescence in pediatric settings and continuing into young adulthood in adult settings. It is a predictable life-course change that affects all youth, especially those with chronic conditions. Even if a youth remains with the same provider into adulthood, preparation for adult-focused care is necessary. Because of the mobility of youth and young adults, the likelihood that they will change providers is almost certain, and thus the need to establish a systematic transition process.

Transition Landscape

United States: National Transition Context

Affordable Care Act

The Patient Protection and Affordable Care Act (ACA), passed in 2010, has accelerated interest in transitional care in general. The Centers for Medicare & Medicaid Services (CMS) has

supported numerous payment and service delivery innovations to improve hospital-to-home transitions. It also established the Communitybased Care Transitions Program for Medicare beneficiaries at high risk of hospital readmission [2]. Further, CMS implemented a new health home-state Medicaid plan amendment to improve transitional care for children and adults with chronic conditions, and 19 states and the District of Columbia had implemented this option at the end of 2015 [3]. Additional transition-related efforts in the ACA include support for accountable care organizations, advanced primary care initiatives, and insurance expansions. These have all contributed to the growing national interest in transition, including pediatric to adult transition.

Healthy People 2020 and Title V National Performance Goals

National goals articulated in Healthy People 2020 and the federal Maternal and Child Health Title V Block Grant call for improving transition support to youth with and without special health care needs. As many as 32 state Title V programs across the country have selected transition from pediatric to adult health care as their priority and are in the process of developing 5-year statewide action plans [4]. Although these programs have historically served only children, many of them are beginning to reach out to adult clinical leaders and their professional organizations. They are also starting to establish quality improvement, consumer education, and training efforts that are aligned with the American Academy of Pediatrics/American Academy of Family Physicians/American College of Physicians (AAP/AAFP/ACP) clinical report on transition [5] and the Six Core Elements of Health Care Transition [6] (described in detail later).

Medical Home Certification Standards and Electronic Health Records Meaningful Use Standards

Other national efforts influencing national attention on transition include the 2014 National Committee on Quality Assurance's medical home standards [7], which calls for the practice to collaborate with the patient/family to develop and implement a written care plan for patients transitioning from pediatric to adult health care. The CMS Meaningful Use Measures call for the use of certified electronic health records (EHR) technology in ways that can be measured to improve quality and safety, including the electronic sharing of a summary of care record for patients moving from one setting of care or provider to another [8].

Youth in Transition

Who Are They?

More than 30 million youth are between the ages of 18 and 24 in the United States [9]. According to the 2011/12 US National Survey of Children's Health, 25 % of the adolescent population, ages 12–17, has a special health care need [10]. Although comparable special needs prevalence estimates are not available for the young adult population, ages 18-24, related literature reveals that at least 30 % of young adults have 1 or more chronic conditions [11], and about 5 % of young adults report having a disability that affects their daily functioning [12]. In sum, there are estimated 9 million young adults in the US with a chronic condition, including 1.5 million with a disability, who are transitioning to adult-centered care.

According to the Institute of Medicine, "young adults are surprisingly unhealthy," as evidenced by the peaking of many risky behaviors in the age group, the onset of serious mental health conditions, unintentional injury, substance abuse, and sexually transmitted infections [13]. Despite these health risks, young adults' utilization of health services is significantly lower than adolescents and adults over the age of 25, and, unfortunately, their emergency room use is higher [14]. In 2014, 25 % of young adults in the US were without a usual source of medical care [14]. Despite improvements in insurance access among this age group as a result of the ACA, their connection to health care is tenuous at best.

What is Their Experience?

Several US national studies have examined the experience of youth and young adults transitioning to adult-focused care. According to the 2009/2010 National Survey of Children with Special Health Care Needs, 60 % of youth with special health care needs are not receiving from their health care providers the necessary preparation to transition from pediatric to adult health care [15]. Those least likely to receive transition support are male; Hispanic; Black; low to moderate income; with emotional, behavioral, or developmental conditions; without a medical home; and publicly insured or uninsured.

Published studies both internationally and in the US consistently show that youth/young adults often feel lost, unclear about the distinctions between pediatric and adult care, confused about the logistics for accessing adult health care, and unprepared about assuming self-care and self-advocacy responsibilities [16–19]. Also, from the youth/young adult perspective, certain adult provider characteristics negatively affect satisfaction with their transition experience, including decision-making opportunities, time alone without parents, and providers' social skills (talking, listening, showing understanding, and honesty) [20].

Without transition support, YSHCN transitioning to adult health are not only at risk of dissatisfaction and unnecessary worry, but also at increased risk for poor health outcomes [21]. The literature shows that youth and young adults are often unable to name their own health condition, relevant medical history, prescriptions, and insurance. Their adherence to care is lower, and medical complications are increased. In addition, many reports having difficulty finding an adult provider willing and interested in accepting them as a new patient, particularly those with developmental disabilities, mental health conditions, and complex medical conditions.

Provider Transition Barriers

Both pediatric and adult providers within the US and internationally identify many obstacles to

offering transition services. The most common barriers are the lack of communication, infrastructure to support care coordination, time and reimbursement, guidelines, and protocols between the two systems [20, 22-24]. In addition, both provider groups report issues with youth/young adult's non-compliance with treatment-lack of disease knowledge, self-care skills, and independence-and challenges addressing psychosocial issues affecting transition-aged youth and young adults [25, 26]. Both groups acknowledge the difficulty that pediatric providers have in breaking the bond with adolescents who have long been in their practice and the difficulty that parents have in ceding decision-making authority to their youth when they are with adult providers [20, 23]. Conversely, adult providers acknowledge that for young adults with more complex chronic conditions, the lack of parental involvement after transfer to adult care is a barrier to transition [20]. Both the provider groups acknowledge that young adults and parents often have unrealistic expectations of adult providers especially around time and attention [20, 27].

There are also barriers specific to each provider group. Pediatric providers consistently cite concerns about adult health care, including lack of confidence in adult care especially around the comparability and organization of care that youth/young adults with special health care needs receive in the adult system [22, 24]. In addition, pediatric providers frequently report difficulty in finding adult providers [24] and, in particular, those with specialized knowledge about young adults with pediatric-onset chronic diseases, including intellectual/developmental and mental health conditions [20, 28].

For adult providers, research studies point to several transition impediments, including the lack of medical records and follow-up recommendations from their new patients' past pediatric providers [29, 30]. Adult providers cite concerns about their limited knowledge and training in pediatric-onset diseases, adolescent development and behavior, and available community resources [22, 31]. In addition, they are concerned that there are not enough adult subspecialty or mental health providers to care for the young adults they accept into their practices [28].

Transition Models/Approaches and Professional Recommendations

Transition Models/Approaches

Transition models are variable in their structure and provider roles, but they align across broad categories of actions needed to improve transition for youth with and without special needs. They usually offer a common set of services: a designated transition coordinator, patient education and activation, a transition plan of care, and assistance with transfer and follow-up. Models often vary in terms of the timing and duration of the transition intervention, the scope of transition planning (e.g., health care primarily or health/ education/employment/independent living), and the patient population involved (typically youth with specific chronic conditions or with complex conditions). Oftentimes transition models are established as separate clinics, typically based on hospital ambulatory settings, located in either the pediatric or adult medical settings where youth at a certain age will obtain the necessary preparation and assistance in moving from one system to the next and can involve being seen jointly by both the pediatric and adult provider.

The action steps within these models fall into the broad categories of preparation, transfer, and post-transfer/integration into adult approach to care. Based on an examination of US and international transition recommendations and systematic reviews, the following summarizes common elements of each of these three action steps:

- 1. Preparation/Planning:
 - Practice policy/approach that is shared with the youth/family
 - Assessment of transition readiness that addresses knowledge of disease and health systems, self-management, and advocacy

- Plan of care that often includes overarching goals in education, independent living, employment along with supporting health goals
- Care coordination across many domains
- Support for independence (e.g., visits alone with health care provider and honoring adult approach to care at age 18), self-management, and self-advocacy through education and sometimes peer support
- Medical summary and emergency care plan
- List/assistance with selecting adult provider, arranging initial visit, and sometimes joint pediatric/adult visits
- Tracking mechanism to assure planning support received
- Designated member of practice who coordinates transition process in pediatric/ adult setting
- 2. Transfer:
 - Transfer package
 - Communication between pediatric and adult provider, including clarification of residual pediatric responsibilities before initial adult visit
- 3. Post-Transfer/Integration into Adult Approach to Care
 - Information/orientation for new patient about adult practice, sometimes including policy, welcome letter, frequently asked questions (FAQs), pre-visit call, and identification of preferred communication methods
 - Follow-up with new young adult patient after transfer
 - Feedback from youth/young adult/family about transition experience

United Kingdom and American Professional Organizations Recommendations

National Institute for Health and Care Excellence (NICE) Guideline, "Transition from Children's to Adults' Services for Young People Using Health or Social Care Services"

NICE develops national clinical guidelines to offer consistent high-quality, evidence-based care for patients using the National Health Service in the United Kingdom. In 2016, NICE published transition recommendations that offer guidance for practitioners in children's and adult health, mental health and social care services, and education and employment [32]. Their overarching principles call for involvement of youth and their caregivers and the provision of a developmentally appropriate, strength-based and person-centered approach. They also recommend children's and adult's service managers work together to develop [32]:

- 1. Joint vision and shared transition protocols
- 2. Early transition planning (ages 13 and 14) with a transition plan
- A designated "worker" to coordinate transition support
- 4. Involvement of young people to build independence with parents and caregivers
- 5. Transfer support and information about the youth's health condition, emergency care, strengths, and future goals
- 6. Support after transfer to ensure engagement with adult care and services
- 7. Senior leadership support, and
- 8. Ongoing feedback, planning and education for all involved.

American Academy of Pediatrics/American Academy of Family Physicians/American College of Physicians Clinical Report on Transition to Adulthood in the Medical Home

In 2011, the American Academy of Pediatrics (AAP), the American Academy of Family Physicians (AAFP), and the American College of Physicians (ACP) published a joint statement describing a recommended clinical approach for transition to adulthood for all youth, not just for youth with special needs [5]. According to this consensus statement, transition planning, "should be a standard part of providing care for all youth and young adults" and "should involve the engagement and participation of the medical home team, the family and other caregivers, and the individual youth should be collaborating in a

positive and mutually respectful relationship." Starting early in adolescence and continuing into young adulthood, Step 1 of this practice algorithm begins with a discussion of the office transition policy with youth and families and an assessment of transition readiness. Step 2 continues with a transition readiness assessment and transition plan of care, and Step 3 involves implementing and updating the plan of care to prepare for adult care. Step 4, beginning at age 18, calls for an adult model of care and assistance in preparing for transfer to an adult provider. Step 5 consists of identifying an adult practice prepared to accept the new patient and coordinating the transfer, and Step 6 is documenting transfer completion. In 2016, the AAP reaffirmed their commitment for the principles in the 2011 Clinical Report and, in 2017, the AAP/ACP/AAFP plan to update the original Clinical Report.

To promote implementation of the Clinical Report, Got Transition, the Center for Health Care Transition Improvement, developed a structured approach in 2011, called the "Six Core Elements of Health Care Transition" with sample tools and transition measurement options [6] (described below). From 2011 to 2013, 5 US transition learning collaboratives piloted this approach and sample tools and demonstrated that the Six Core Elements approach and tools were feasible and adaptable for use in a variety of primary and specialty clinical settings and resulted in measurable improvements in the health care transition process [33]. In 2014, the original Six Core Elements were updated based on the learnings from the national quality improvement projects, the literature, and reviews from more than 100 provider and consumer experts [6].

The Six Core Elements define the basic components of health care transition support. Providers can choose to implement all or only a few core elements according to their patients' needs and available practice resources. They can also choose to customize the sample tools to align with practice policy, disease-specific interests, and other patient population needs.

For *adult practices*, the Six Core Elements include: (1) a transition and young adult care

policy, (2) tracking and monitoring, (3) orientation to adult practice, (4) integration into adult approach to care, (5) initial visit, and (6) ongoing care.

For *pediatric practices*, the Six Core Elements are slightly different and consist of: (1) a transition policy, (2) a method for tracking and monitoring, (3) a transition readiness assessment, (4) transition planning, (5) transfer of care, and (6) transfer completion (see Fig. 1.1).

For providers who care for youth throughout the lifespan, such as family practitioners and med-peds-trained providers, the Six Core Elements offer ways to transition to an adult approach to care at age 18 and, if needed in the future, preparation for a new adult provider.

Specifically, for adult providers who are accepting a young adult, consider the following ways to implement the six core elements (examples of the tools mentioned can be found at www.gottransition.org): Create a transition policy that will inform the young adult what to expect when coming to your practice, especially around confidentiality and consent, and share with all new young adults with chronic conditions of childhood (YACCC) patients. Create a welcome letter with office FAQs and share with pediatric practices who could offer it to their

patients as they are planning to transfer to your practice, or give the welcome letter and FAQs along with the transition policy to the YACCC at the initial visit and discuss any questions they might have with regard to interfacing with you and your practice. As YACCC often do not follow-up consistently and are tech savvy, discuss with YACCC ways that your office can contact them for appointments such as texting them reminders and connecting them to your online chart information if available. If the YACCC does not come with a readiness assessment done by the pediatric office, consider giving a self-care assessment to the YACCC at the first or second visit to learn what aspects of their health and adult health care they do not know. A plan for gaining the knowledge needed from the self-care assessment can be added to their plan of care. This self-care assessment can be repeated during the first year the YACCC is in the practice to be sure they are prepared to take better care of their health. To further engage YACCC in their care, consider giving a follow-up survey asking YACCC how the integration into your practice went so they understand that your practice is interested in their opinion about how to improve the transition process in your practice.

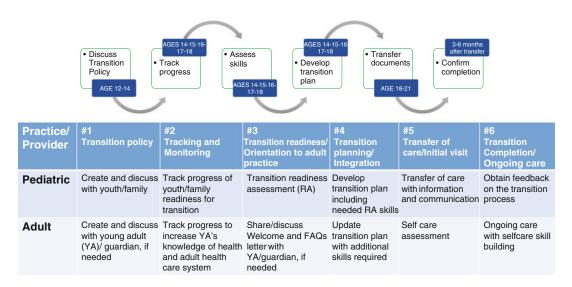


Fig. 1.1 Summary of six core elements of transition approach and timeline for pediatric and adult practices

Starting a Transition Improvement Process and Measuring Impacts

To transition patients more effectively, a team-based approach is needed where both the pediatric and adult provider teams are engaged with the process. Quality improvement strategies have been shown to improve health care processes and can be used by pediatric and adult provider teams to improve transition care for YACCC.

Starting a Transition Improvement Process

Much has been written about implementing practice improvements, particularly related to the US medical home model [34]. Many of these same steps apply to transition whether in primary or specialty practices or within different insurance schemes such as a US health plan or accountable care organization. There are several guiding principles that serve as a foundation for all transition efforts: they should involve youth and parent consumers; they should be person-centered, and culturally and developmentally appropriate; they require collaborations between pediatric and adult providers/systems; and they should be part of routine care and linked to insurance coverage and other community-based transition supports.

Got Transition: Center for Health Care Transition Improvement has a practice resource on starting a quality improvement transition process [35]. This resource describes four steps: (1) securing senior leadership support, (2) forming a transition improvement team, (3) defining transition processes for improvement, and (4) dedicating time to implement transition improvements. Other key lessons learned from implementing transition quality improvements with pediatric and adult sites and health plans confirm the significance of customizing the tools that will be used for transition planning, transfer, and integration. This process ensures buy-in and enables sites to ensure that their patient population needs are addressed and that practice and state-specific information is incorporated, as needed. Another critical lesson is that starting a transition process may involve distinct patient populations—those who are 18 and older and need to transfer relatively quickly, those who are new young adult patients and who have received no orientation to adult care, and those who are ages 12–14 with whom clinicians have the time to plan for a smooth transfer and integration into adult care. More lessons have been summarized in recent quality improvement efforts directed by Got Transition [33, 36].

Measurement Options for Assessing Quality, Experience, and Costs

A 2014 systematic review of transition measures identified the range of "Triple Aim" measures used in published studies with a rigorous evaluation design [21]. This study concluded, however, that "transition programs are inconsistently evaluated in terms of their impact on population health, patient and provider experience, and cost [21]". Despite the nascent field of pediatric to adult transition evaluation, there are several options for measuring transition performance among individual providers, practices, and networks/systems. With respect to transition process measurement, the Six Core Elements include two options for measuring implementation of the Six Core Elements: (1) the "Current Assessment of Health Care Transition Activities" is a qualitative self-assessment method for determining the level of health care transition support currently available and (2) the "Health Care Transition Process Measurement Tool" is an objective scoring method for assessing implementation of the Six Core Elements. Either one of these tools can be used in transition quality improvement initiatives as a baseline measure and then repeated periodically to assess progress.

With respect to *transition measures related to population health*, there are several that could be considered, including self-care skills, adherence to care, and continuity of care (including medications). Other population health measures, such as disease-specific measures, quality of life, and mortality have been used to evaluate transition performance. However, the extent to which transition interventions should be held accountable for potentially influencing these outcomes is a subject of debate. Certainly, these measures are important to assess in terms of the provision of care in general.

With respect to transition consumer experience measures, the Six Core Elements includes a "Health Care Transition Feedback Survey" that can be used in full or part to elicit youth, young adult, and/or parent experience regarding transition preparation, transfer, and integration into adult care. Another consumer experience instrument, the "Mind the Gap Scale," has been used in transition studies for youth with arthritis [37]. There is a dearth of measures/instruments for eliciting provider experience in implementing specific transition approaches. One study, using a structured interview format, obtained provider feedback on implementing the Six Core Elements [33]. Specifically, clinicians were asked about the quality improvement process, implementation of each core element, major challenges, and potential for spread of transition. For the most part, published literature is limited to describing common barriers impeding the provision of transition services.

With respect to measures for utilization and costs, there are several options to consider, including changes in the use of ambulatory care, emergency rooms, and hospitalizations. What is intended for transition is that more youth and young adults have a usual source of sick and preventive care; more make an annual preventive/primary care visit; the time between the last pediatric visit and the initial adult visit is reduced; and the no-show rate among young adults is lowered. All of these intended effects are measurable, including their associated costs.

United States Training Competencies Related to Transition

Adult providers, as described previously, are interested in training in the specific diseases they had little exposure to during training [22, 30]. They also welcome consultative support from

their pediatric colleagues. An important transition educational effort is being conducted by the American College of Physicians (ACP) Council on Subspecialty Societies (CSS). They partnered with Got Transition and formed specialty society work groups to customize the Six Core Elements for particular condition groups to strengthen internists' ability to care for young adults with congenital or childhood-onset conditions. The specialty societies' subgroups customized at least three tools from the six Core Elements: (1) a transition readiness assessment (for use in pediatric care), (2) a self-care assessment (for use in adult care), and (3) a medical summary/transfer record containing the essential information needed for communication between pediatric and adult clinicians for practices. These new condition-specific transition tools are now available and were developed for use in general and specialty practices caring for transitioning patients [38].

Professional societies have made available modules and curriculum for residents both in pediatrics and internal medicine. The American Academy of Pediatrics offers a series of five case-based educational modules designed to be incorporated into existing curriculum by pediatric residency program directors and faculty. The modules focus on educating residents about characteristics and benefits of the patient- and family-centered medical home, care coordination, care planning, transition to adult care, and team-based care [39]. In addition, the Association of American Medical Colleges has a transition case scenario called But Tommy Likes It Here: Moving to Adult Medicine available on their Website [40]. This case discusses the process for a transition for a youth with a chronic illness covering barrier and resistance issues that may be encountered and how a physician could handle the issue. The case suggests areas of discussion such as age-appropriate care, handling of intrusive parents, feelings of the patient and provider, and problem-solving skills. The Medicine-Pediatrics Program Directors Association, through a Health Resources and Services Administration-funded effort in 2013–2015, developed a transition curriculum for primary

care residents that incorporate training around the needs of YSHCN and the transition process and shows where the learning objectives demonstrate components of the Six Core Elements (publication forthcoming).

There are examples of training approaches within adult medicine residency programs that can address training in childhood-onset diseases. Studies have been conducted with internal medicine residents about their exposure and preferences around transition from pediatric to adult health care. They have shown that internal medicine residents receive little exposure to transition issues or young adult patients in their training [31, 41], and they prefer to receive their education mainly through clinical exposure and case discussions. Several academic medical centers have started joint pediatric and adult residency training sessions addressing transition and caring for young adults with congenital or childhood-onset conditions, such as Brigham and Women's Hospital and Boston Children's Hospital (The WISHES project) [41] and the George Washington University Medical Center and Children's National Medical Center in Washington, DC. Other training approaches include exposing internal medicine residents to young adult patients in continuity clinics so that they can gain experience in caring for this distinctive age group or offering electives in college/university health clinics so residents can learn if they have a special interest in caring for this population.

Payment for Transition Services Within the United States Health Care System

Payment for the added time, training, and infrastructure necessary to ensure effective transition to adult care is typically cited as one of the most important concerns affecting adult and pediatric providers in the US. Costs associated with transition quality improvements, electronic medical records (EMR) modifications, consumer outreach, and health professional training related to transition and to the care of young adults with childhood-onset conditions are seldom covered, except through grant mechanisms. Non face-to-face services, including care coordination, identification of adult specialists, and care plan development are seldom compensated. To overcome these payment barriers, multiple strategies need to be considered.

Improvements in Coding and Reimbursement

Several important options are currently available for adult physicians to code and are described in a Got Transition Practice Resource [42]. To assess a new patient's self-care skills, adult practices can bill under CPT 99420 so long as they are using a standardized scorable tool, such as Got Transition's Self-Care Assessment Tool [43] or the Patient Activation Measure. To develop or update a plan of care that incorporates transition, adult practices can use either the CPT code for care plan oversight services (CPT 99339-40) or for complex chronic care managements services (CPT 99487-90). To educate new patients about self-care skills, several codes are available, including CPT codes for office visits (CPT99211-15), prolonged services (993544-55), or education and training services for patient self-management (CPT 99860-62). To provide hospital-to-home transition support, there is a relatively new transitional care management services code (CPT 99495-96) that covers a bundled set of face-to-face and non face-to-face services. Other codes that may be part of transition support include interprofessional telephone and Internet consultations (CPT 99446-49), online medical evaluation (CPT 99444), telephone services (CPT 99441-43), and medical team conference (CPT 99366). Coding for services does not equate with reimbursement. However, without accurate coding, reimbursement will never be possible. Practice contract negotiations and affiliation with state ACP, AAFP, and AAP chapters are critical in order to address transition payment gaps.

Because of the tremendous workforce shortages among adult primary care providers, payers and plans may be receptive to alternative payment strategies to expand the availability of adult providers willing to care for young adults with complex medical conditions, intellectual/ developmental disabilities, and/or mental health conditions. The set of payment options are described in detail elsewhere [42]. For example, payers may want to experiment with bonuses for adult practices willing to accept a certain volume of new young adult patients with chronic conditions tied with care coordination support and pediatric consultation support. Recognizing the added complexity of serving young adults with high no-show rates, payers may want to consider monthly care management fees to ensure that this vulnerable population is adequately oriented, with active outreach and follow-up. Another payment innovation that payers could consider is a pay-for-performance strategy linked to improvements made in the use of the Six Core Elements or to evidence of shared accountability between pediatric and adult providers for transfer and integration into adult health care.

Infrastructure Funding

Aligning with the increased interest in transition, opportunities for infrastructure investments may be possible by linking with hospital-to-home transition efforts, accountable care organizations, medical or health home efforts, Medicaid performance improvement efforts, state innovation models, care coordination programs, and state Title V programs for children with special needs, many of whom are reaching out to partner with adult providers and state medical professional organizations and training programs.

Conclusion

Many transition improvements are being introduced into clinical practice and training programs to address the inherent challenges in moving from pediatric to adult health care. These improvements—directed at transition preparation, transfer, and integration into adult care/post-transfer—are based on professional consensus recommendations, the new tested quality improvement approach ("Six Core Elements"), and a broad set of US and international transition interventions. Progress in measuring and paying for pediatric to adult care transitions is still in its infancy, however.

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