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## Pediatric to Adult Transition: A Quality Improvement Model for Primary Care



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### A B S T R A C T

**Purpose:** To examine the relationship between quality improvement activities with pediatric and adult primary care practices and improvements in transition from pediatric to adult care.

**Methods:** This was a time-series comparative study of changes in pediatric and adult practices involving five large pediatric and adult academic health centers in the District of Columbia. Using the Health Care Transition Index (pediatric and adult versions), we examined improvements in specific indicators of transition performance, including development of an office transition policy, provider knowledge and skills related to transition, identification of transitioning youth, transition preparation of youth, transition planning, and transfer of care.

**Results:** Improvements took place in all six transition quality indicators in the pediatric and adult practices that participated in a 2-year learning collaborative to implement the "Six Core Elements of Health Care Transition," a quality improvement intervention modeled after the American Academy of Pediatrics/American Academy of Family Physicians/American College of Physicians Clinical Report on Transition. All sites established a practice-wide policy on transition and created an organized clinical process for tracking transition preparation. The pediatric sites conducted transition readiness assessments with 88% of eligible youth and prepared transition plans for 29% of this group. The adult sites conducted transition readiness assessments with 73% of eligible young adults and developed plans for 33%. A total of 50 were transferred in a systematic way to adult primary care practices.

**Conclusions:** Quality improvement using the Six Core Elements of Health Care Transition resulted in the development of a systematic clinical transition process in pediatric and adult academic primary care practices.

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### IMPLICATIONS AND CONTRIBUTION

Few studies have been published about quality improvement approaches that involve a partnership between pediatric and adult practices in the transition and transfer of youth from pediatric to adult-centered care. This transition learning collaborative demonstrates that implementation of the "Six Core Elements," which are aligned with the American Academy of Pediatrics/American Academy of Family Physicians/American College of Physicians Clinical Report, can be successfully implemented in pediatric and adult sites.

**Conflicts of Interest:** The authors have indicated that they have no financial relationships relevant to this article or conflicts of interest to disclose.

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Although much has been written about measurement of medical home models in pediatric and adult practices, little has been published about effective quality improvement (QI) interventions for transitioning youth from pediatric to adult-centered health care [1]. Published transition literature describes a variety of transition

approaches often starting late in adolescence and almost exclusively for youth with specific chronic conditions [2–9]. Furthermore, these articles primarily target pediatric providers but not adult providers. Because of the relatively recent publication of the American Academy of Pediatrics/American Academy of Family Physicians/American College of Physicians (AAP/AAFP/ACP) Clinical Report on Transition from Adolescence to Adulthood [10], the use of their recommended transition algorithm has, at this time, not yet been incorporated into published transition studies.

According to the 2011 Clinical Report, a planned transition process should begin early in adolescence (ages 12–14 years) for all youth, including those with special health care needs. Starting with a discussion of the practice's policy on transition with youth and parents, the process continues over time to ensure readiness and planning for adult-centered care at age 18 and for transfer to an adult provider, if needed, before the age of 22 years. This transition process goes on until youth and young adults are integrated into an adult model of care [10]. According to the AAP/AAFP/ACP, transition should be a part of routine primary and specialty care with specific collaborative roles for pediatric, family medicine, and internal medicine practices.

After the release of the Clinical Report, the federally funded national resource center on transition (Got Transition) developed the "Six Core Elements of Transition," which are aligned with the algorithm specified in the Clinical Report. These core elements (Figure 1) define a sequential clinical process with a sample set of tools for use by pediatric and adult practices.

This article presents findings related to implementation of the Six Core Elements of Health Care Transition. Our aim was to determine whether pediatric, family medicine, and internal medicine practices participating in a 2-year learning collaborative (LC) would improve the delivery of transition services for youth with chronic conditions.

## Methods

This study involved five large academic primary care practices in the District of Columbia (Washington, DC) that participated in

a transition LC between 2011 and 2012. Two were adolescent clinics (with 11,000 visits/year and 1,830 visits/year); one was a pediatric clinic (with 15,000 visits/year); one was a family medicine resident clinic (with 10,000 visits/year); and one was an internal medicine clinic (with 35,000 visits/year). Each practice formed a team consisting of a lead physician, a care coordinator who focused on transition (nurse, social worker, or family navigator), and a consumer (parent/caregiver or young adult). The majority of the pilot patient population was low income, between the ages of 14 and 24 years, insured by Medicaid, and enrolled in a Medicaid managed care plan (Health Services for Children with Special Needs, Inc., Washington, DC) serving children and young adults (ages 0–26 years) with chronic physical, developmental, and mental health conditions. The vast majority were African-American.

The LC used the Institute for Healthcare Improvement's "Breakthrough Series" Model [11], and teams attended five 1½-day learning sessions combined with regular "coaching" calls and on-site visits. Over the 2-year period, monetary support in the amount of \$36,000 was provided to each practice site to cover a small portion of staff time and consumer participation. Faculty with expertise in transition, medical home, and consumer engagement provided training support using the Six Core Elements as a guide and toolset with sample tools for each core element [12]. The Health Care Transition Index [13,14], modeled after the Center for Medical Home Improvement's Medical Home Index [15], was used to assess progress in implementing the Six Core Elements (Supplementary Figures 2 and 3). For each core element, practices assessed their level of progress along a continuum from Level 1 (basic) to Level 4 (comprehensive), and within each of the 4 levels, practices assessed if they were partially or fully completed. Each level was defined by a brief narrative description, and practices indicated whether they partially or completely performed the activities. Each core element had a possible score of 1 through 8 or from Level 1 to Level 4. The range of possible raw scores was 6 (all six indicators at Level 1—partial) to 48 (all six indicators at Level 4—complete). The Health Care Transition Index was administered three times

Transition Intervention: "Six Core Elements for Health Care Transition"	
Pediatric Health	Adult Health
1. Transition Policy	1. Privacy and Consent Policy (adult-centered care)
2. Transitioning Youth Registry	2. Young Adult Patient Registry
3. Transition Preparation (use of transition readiness assessment)	3. Transition Preparation (continuation of transition readiness assessment)
4. Transition Planning (use of portable medical summary with transition action plan)	4. Transition Planning (continuation of transition action plan and updating of portable medical summary)
5. Transition and Transfer of Care (transition or transfer to adult model of care, transfer checklist, communication with adult provider, and, if needed, shared care with adult provider)	5. Transition and Transfer of Care (review of transfer of care package and consultation with pediatric provider as needed)
6. Transition Completion (documentation of transfer)	6. Transition Completion (documentation of transfer and initiation of care)

Figure 1. Transition intervention: "Six Core Elements for Health Care Transition."

over the course of the project by the project codirector (P.W.). Each team completed the Index, and the scoring was reviewed with each lead physician to ensure consistency in interpreting the Health Care Transition Index descriptors and to eliminate reporting bias.

We compared the results of the Transition Index at three points in time over a 22-month period between February 2011 and December 2012. We analyzed the average scores (ASs) for the four pediatric practices, which included two adolescent sites, one pediatric site, and one family medicine site, which cared for pediatric patients. The two adult practices included one internal medicine site and the same one family medicine site, which also accepted new adult patients (Table 1).

## Results

### Office policy on transition

At the outset of the project, all participating sites were at the basic level (AS = 1.2) with respect to an office policy on transition. None of the pediatric practices had a written transition policy, and adult practices had no privacy or consent policy beyond the Health Insurance Portability and Accountability Act (HIPAA) policy routinely given to patients. Between Times 1 and 2, practices made substantial changes (AS = 4.8). Written policies were developed and tested by each transition team, with consumer input, before seeking formal departmental and legal approval. The transition policy typically described the practice-wide approach to transition, including age when transfer out of the pediatric medical home takes place. The privacy and consent policy referenced HIPAA requirements and discussed changes at age 18 regarding privacy as part of adult-centered care, alternative decision-making options for those with intellectual disability, access to personal health information, and consent for care. At the end of the LC, practices had further improved and were beginning to proactively communicate their policy to

**Table 1**  
Comparison of transition index scores by core element in pediatric and adult sites

Core element	Average score	Average pediatric score	Average adult score
<b>Policy</b>			
Pre-LC	1.2	1.3	1.0
Mid-LC	4.8	5.3	4.0
Post-LC	5.7	6.3	4.5
<b>Staff knowledge</b>			
Pre-LC	2.0	2.0	2.0
Mid-LC	5.2	5.3	5.0
Post-LC	5.5	5.5	5.5
<b>Registry</b>			
Pre-LC	1.5	1.3	2.0
Mid-LC	5.8	6.0	5.5
Post-LC	5.3	5.3	5.5
<b>Preparation</b>			
Pre-LC	2.7	3.0	2.0
Mid-LC	5.7	6.0	5.0
Post-LC	5.5	5.7	5.0
<b>Planning</b>			
Pre-LC	1.7	2.0	1.0
Mid-LC	4.2	4.5	3.5
Post-LC	3.3	3.5	3.0
<b>Transfer</b>			
Pre-LC	2.7	2.5	3.0
Mid-LC	5.3	6.3	3.5
Post-LC	5.5	5.8	5.0

LC = learning collaborative.

youth, parents, and young adults. Pediatric practices, for example, gave out their policy to youth and parents via encounters, brochures, posters, and Web sites. None of the practices reached the comprehensive level, which required documentation in the electronic health record (EHR) that decision making and information access rights are clearly specified by age 18. Compared with adult practices, participating pediatric practices scored higher as a result of more widespread dissemination of their policy to patients.

### Staff and provider transition knowledge, skills, and coordination of care

When the LC started, staff knowledge about transition was assessed at Level 2. That is, knowledge was variable and dependent on an individual's interest. By Time 2, scores more than doubled (AS = 5.2). All participating teams were aware of the AAP/AAFP/ACP Clinical Report and the recommended transition algorithm. At the end of the LC, small additional improvements were made (AS = 5.5). None of the practices attained the highest score of 8, which required explicit youth/parent partnerships, care coordination support to oversee transition planning, available information and community resources on transition, and integration of the Six Core Elements into EHRs. Small differences were reported between pediatric and adult practices Time 2, but no differences were found at the project conclusion.

### Registry

Participating sites were at the basic level (AS = 1.5). At Time 2, all sites made significant improvements (AS = 5.8). Written registries were developed to identify and track a subset of transitioning youth, ages 14 years and older, mostly but not exclusively Health Services for Children with Special Needs' members. At Time 3, pediatric registry scores declined slightly (AS = 5.3); no changes took place in adult practices, largely because of the added effort to transfer those more than 21 years of age. A total of 400 transitioning youth and young adults were included in pediatric registries and 128 in adult registries. None of the practices were able to integrate an electronic registry to systematically track implementation of all transition steps. The difference between pediatric and adult scores at Time 2 was largely because of delays in transferring pediatric patients to adult sites. At Time 3, adult sites scored slightly higher as they began adding to their registries young adult patients with chronic conditions from within their own practices.

### Transition preparation

When the project started, teams reported an AS of 2.7. That is, youth usually had time alone with their doctor with the exception of patients needing alternative decision-making support. By Time 2, all sites were assessing transitioning youth and young adult patients about self-care management and health system navigation skills using a standardized transition readiness assessment tool that was part of the Six Core Elements sample tools (AS = 5.7). The transition readiness assessment was typically administered as part of a routine preventive care visit, less often as part of a chronic care visit. At the end of the project, a slight decline was reported (AS = 5.5), mostly attributable to practices better understanding what they were trying to

accomplish and scoring themselves more rigorously. Over the course of the project, the four pediatric sites conducted 352 transition readiness assessments (88% of those in their registries), and the two adult sites conducted 93 (73% of those in their registries). None of the practices used a designated transition care coordinator to solidify patients' self-care management skills beyond the education that was part of regular preventive or chronic care office visits. Pediatric practices scored higher than adult practices on transition preparation because of the fact that this core element is primarily a pediatric responsibility.

### *Transition planning*

At the beginning of the LC, practices were assessed at the basic level (AS = 1.7). That is, in pediatric practices, adolescents and parents were expected to identify their preferences for an adult provider. In the adult practices, office staff answered basic questions about their practice. At Time 2, all practices progressed (AS = 4.2), with pediatric practices starting at age 14 to inform and remind youth and their families about the practice's transition policy and HIPAA requirements. Adult practices informed their new young adult patients about the practice's approach to care and provided an opportunity to answer questions. Progress declined by Time 3 (AS = 3.3) in large part because of practices' recognition of the added effort to provide transition support. Although the pediatric sites prepared a transition plan for 117 patients (29%) and the adult sites for 42 patients (32%), none of the sites developed transition plans for the majority of transitioning patients, and none were able to incorporate this information into their EHR. All practices scored the lowest on the transition planning core element.

### *Transfer of care*

At the outset of the LC, practices scored the highest on transfer of care (AS = 2.7). Pediatric sites reported that youth and families were encouraged to see an adult primary care provider when the youth approached the practice age limit, and adult sites provided information to new patients about how to make an appointment. By Time 2, 15 months later, much progress had been made (AS = 5.3). Pediatric practices maintained a list of adult primary care providers prepared to take at least some of their older youth with chronic conditions, and they also assisted some of these patients in the transfer of pediatric specialty care. Adult teams provided information to new young adult patients to prepare them for an adult model of care and inquired if special accommodations were needed before the first appointment. Over the course of the 2-year LC, 50 youth and young adults with chronic conditions were transferred into adult practices including but not limited to the participating adult sites. These patients were transferred with an updated medical summary, a transition readiness assessment, and sometimes with a transition plan and chronic condition fact sheet as the "transition package." Importantly, adult sites formalized a process of medical record transfer and communication with referring pediatric providers. At the beginning, none of the pediatric practices had an extensive list of adult primary care providers prepared to accept their transferring patients, and a transfer package was rarely and inconsistently completed for youth with chronic conditions needing to transfer. Pediatric practices scored higher on this core element, especially at Time 2, primarily because

relatively few pediatric patients had been transferred to adult sites by that time.

### *Quality improvement lessons learned*

At the last LC session, each of the five teams participated in a structured interview to provide feedback on the QI process, implementation of each core element, major challenges, and potential for spread of transition. All the sites agreed that having the Six Core Elements and sample tools to guide the clinical process made the process possible. They also highlighted the significance of senior leadership support not only from medicine but also from nursing and social work. Approaching transition QI as a team-based activity, not as a physician-only process, was essential as well. However, setting aside regular times to work as a team was often a challenge. When families and young adults were involved as navigators or advisors, there was greater buy-in although it was difficult to sustain consumer participation in all but one of the practices.

Certain elements of transition were more difficult and time consuming to implement than others. For example, obtaining institutional approval for a transition policy was time consuming and required senior leadership and legal reviews. Publicly posting the policy and consistently sharing it with youth, young adults, and families was an unanticipated hurdle. Although all sites used a registry to track receipt of the core elements, it was usually maintained by the lead physician and not part of the practice EHR. Transition readiness assessments were readily adopted in all sites and conducted by residents, physicians, nurses, and family navigators. Incorporating these assessments into the EHR as a prompt with links to the plan of care was not achieved over the course of this QI project. Care plans and medical summaries were time consuming and usually completed before transfer. All sites concurred that having an organized pediatric/adult transfer process at the outset made this work more effective and efficient. Each site ended up designating a staff person to ensure that the transfer was coordinated, and all the necessary information on the transfer checklist was provided.

The biggest challenges noted for sustainability were the lack of payment for the added transition work, lack of functionality of EHRs for the transition core elements, and lack of care coordination infrastructure, particularly at the adult sites. Importantly, all the sites concurred that implementing the core elements of transition benefits everyone and the earlier the process begins the better the expectations and results. The adult sites, initially viewing their role as just receiving new transfer patients, soon began to focus greater attention within their respective practices on viewing young adults as a unique population, including adapting their practice welcome information, pre-visit reminders, and visit approaches for this population. It was also found that identifying adult providers interested in caring for this population within the adult practice, identifying a point person for appointments in the adult practice, and requiring that the transfer checklist was completed before the first adult visit contributed greatly to the success of transfer.

## **Discussion**

Substantial improvements were made in transition clinical processes in both pediatric and adult practices using the Six Core Elements of Health Care Transition. All pediatric and adult sites

established formal practice-wide policies on transition and more clearly informed youth, parents, and young adults about privacy and consent as a basic tenet of adult-centered care. All sites created a systematic method for tracking transitioning youth with chronic conditions, and the vast majority conducted a transition readiness assessment of patients in their registry. In addition, transition plans were developed by pediatric and adult practices for about a third of their eligible patients. Fifty youth with chronic conditions were transferred in a systematic way to adult practices. As of July 2014, four of the five participating practices continue to use the Six Core Elements as part of their routine primary care. The family medicine site that did not sustain the transition intervention cited physician staff changes as the main reason.

As the first transition QI project evaluating the use of the Six Core Elements, these positive results indicate the feasibility of an organized transition process between pediatric and adult primary care. All the participating sites were large and busy academic clinics where the transition process had previously not been efficiently coordinated. Professional relationships between participating pediatric and adult teams were new when the project began and were strengthened around shared goals over time.

Differences in transition processes and results between pediatric and adult sites are important to consider for future QI efforts. Two of the three pediatric sites had many over the age of 18 years and several over the age of 21 years needing to transfer. For this population, there was little time for advance transition planning, and, consequently, these were often the most reticent patients to transfer to adult sites. When pediatric sites introduced the core elements to their patients and families early in adolescence, as called for in the Clinical Report, the potential for effectively preparing youth for adult-centered care and transfer was much more promising. At the outset of the LC, all the participating sites presumed that the pediatric practices had the bulk of responsibility for transition. Over time, it became clear to all that both pediatric and adult sites have many common and distinctive roles to play in implementing each core element, a few of which are best done in partnership.

The role of the family medicine practice in this LC, as elsewhere, has both sides of the transition equation to complete. For example, they developed two separate transition policies and two separate readiness assessment (pediatric) and self-assessment (adult) tools. Because of the increased work, it took the family medicine clinic more time to adapt the tools, obtain approval from the larger system, and utilize them. At least, initially, the family medicine practice perceived its role as small because there was no change in providers. Over time, it became clear that their role is greater than either the pediatric or adult site.

Participating adult sites primarily serves adults aged 40 and older, most of whom have chronic conditions. Because youth and young adults, ages 18–25 years, represent such a small proportion of their patient panels and a very high proportion of those with no-show rates, it was more challenging than in the pediatric sites to make transitioning young adults an area of interest among clinicians in the practice. It was consequently decided that, in fact, to succeed it was the best if a group of clinicians self-selected to care for young adults. Internal medicine's challenge early on was fully appreciating the uniqueness of the young adult patient population. For example, the internal medicine team developed, after several plan-do-study-act cycles, an appropriate transition policy and welcome letter but never fully adapted the readiness skills assessment for young adults. Adapting the

readiness assessment skill tool for youth to a young adult self-assessment tool was a major request for and has been completed in the new version of the Six Core Elements available at Got Transition.

The limitations of this QI study pertain to the small number of participating sites (five) and to the relatively small number of youth and young adults in the project—400 in the three pediatric sites and 128 in the two adult sites. All the sites were academic health centers in the District of Columbia; there was neither a mix of primary and specialty practices nor was there a large and diverse geographic area represented. All the participating youth and young adults were low income and had disabling conditions that qualified them for the Supplemental Security Income Program. Despite these limitations, this QI initiative was intended to demonstrate implementation of a set of core transition elements; it was not intended to evaluate patient outcomes resulting from transition.

In conclusion, this QI initiative revealed the success of implementing an organized approach from pediatric to adult health care using the Six Core Elements of Health Care Transition. Further study will be needed to examine these transition processes at a larger scale and to measure their impact on patient outcomes.

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M.M. conceptualized and interpreted the quality improvement results, drafted the background and results for the initial article, and approved the final article submitted. P.W., W.C.C., and J.W.M. made substantial contributions to the design and measurement of the quality improvement model, acquisition and interpretation of results, drafting the article, and gave approval of the final article as submitted. A.B., B.D., K.H., N.Q., and L.T. made significant contributions to the analysis and interpretation of pediatric and adult site results, critically reviewed the article, and have given final approval of the article. The authors appreciate the expert assistance of Corinne Dreskin and Daniel Beck from The National Alliance to Advance Adolescent Health; Mallory Cyr and Ann Walls from the National Health Care Transition Center; Marie Mann from HHS' Maternal and Child Health Bureau; Margaret Copemann and Vinetta Freeman from the DC Department of Health; Danny Bellamy, Cyd Campbell, and Robin Pirtle from Health Services for Children with Special Needs; Jennifer Gode, Eve Lake, Angela Gerst, and Ilana Spitz from the Children's Hospital National Medical Center's Adolescent Clinic; Yan Orellana and TjaMeika Davenport from Children's Adams Morgan Center; Maria Aramburu, Janet Osherow, and Drucilla Howard from Georgetown's Adolescent Clinic; Luis Nunez-Gallegos and Blesilda Licud from Howard University Hospital's Family Health Clinic; and Lauren Leatherman, Sarah Doaty, and Nikki Owens from George Washington's Internal Medicine Clinic.

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### Supplementary Data

Supplementary data related to this article can be found at <http://dx.doi.org/10.1016/j.jadohealth.2014.08.006>.

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