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Better Health, Less Spending: Redesigning the Transition From Pediatric to Adult Healthcare for Youth with Chronic Illness

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Abstract

Adolescents and young adults (AYA) with serious chronic illnesses face costly and dangerous gaps in care as they transition from pediatric to adult health systems. New, financially sustainable approaches to transition are needed to close these gaps. We designed a new transition model for adolescents and young adults with a variety of serious chronic conditions. Our explicit goal was to build a model that would improve the value of care for youth 15–25 years of age undergoing this transition. The design process incorporated a review, analysis, and synthesis of relevant clinical and health services research; stakeholder interviews; and observations of high-performing healthcare systems. We identified three major categories of solutions for a safer and lower cost transition to adult care: (1) Building and supporting self-management during the critical transition; (2) Engaging receiving care; and (3) Providing checklist-driven guide services during the transition. We propose that implementation of a program with these interventions would have a positive impact on all three domains of the triple aim – improving health, improving the experience of care, and reducing per capita healthcare cost. The transition model provides a general framework as well as suggestions for specific interventions. Pilot tests to assess the model's ease of implementation, clinical effects, and financial impact are currently underway.

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Background

Life expectancy has increased dramatically for a wide range of childhood-onset medical conditions, enabling many affected children to survive into adulthood. Increased survival of extremely premature infants,¹ expanded surgical options for patients with congenital heart defects,^{2,3} and improved treatment of genetic disorders such as cystic fibrosis⁴ and sickle cell disease⁵ are salient examples of advances that contribute to this trend. Although these breakthroughs represent a triumph of modern medicine, they introduce a new and growing challenge as an increasing number of adolescents and young adults (AYA) with childhood-onset chronic illness transition from pediatric to adult-oriented healthcare.

Organizational Context

A healthcare delivery innovation lab was established in 2010 at a major academic center with the mission of developing more affordable ways to deliver better healthcare for conditions consuming a significant portion of U.S. healthcare spending.⁶ Guided by national experts, the lab leadership recognized healthcare transition in AYA with chronic illness as an emerging clinical and economic challenge. A design team was assembled to create a new transition care model that would provide high quality, evidence-based care and lower per capita health spending for this population. The team included two physicians, a clinical psychologist, and an economist, each contributing expertise from their field to reach unique solutions to the complex problem of transition. The new delivery model was presented to health systems leaders to discuss opportunities for implementation, evaluation, and refinement.

Problem

During the transition to adult care, AYA with chronic illness experience lapses in care as well as increased rates of emergency room visits and costly, avoidable hospitalizations.^{7,8} Studies have documented poor health outcomes associated with transitions in care, including elevated glycosylated hemoglobin in patients with type 1 diabetes,⁹ increased frequency of sickle cell crises,¹⁰ loss of transplanted organs,¹¹ and, in extreme cases, death.¹² Treatable mental health conditions, particularly anxiety and depression, are common comorbidities of chronic illness in AYA¹³ and are associated with poor health status¹⁴ and greater cost compared to chronic illness without comorbid mental health conditions.¹⁵

This transition from pediatric to adult-oriented care is especially difficult because it occurs at a time when young people face numerous life changes, including education, employment, relationships, and living arrangements. Young adults historically have higher rates of uninsurance, decreased access to regular sources of care, and worse overall health status compared to either children or adults in their 30s and 40s.^{16–18} Yet despite the need, it remains challenging to provide high quality transition care due to lack of financial incentives for services such as care coordination and limited accountability for health outcomes when AYA change providers or transition to new insurance plans.

Consensus statements outlining the importance and key components of optimal transition care were released by several professional organizations* in 2002 and 2011.¹⁹ Despite the calls for action, a recent survey indicated that 60% of youth with special healthcare needs do not receive core elements of care recommended during this vulnerable time.²⁰ Additionally, few transition interventions described in published literature include cost and outcomes data.^{20–22}

Many existing transition programs have been designed within a single clinic or disease process.²³ Such an approach may leave young people with especially rare conditions (e.g. genetic and metabolic disorders) without transition services. Because of the heterogeneity and low prevalence of many childhood-onset illnesses,²³ we aimed to create a model for a wide variety of chronic conditions with an explicit focus on addressing all three elements of the Institute for Health Care Improvement's "triple aim" of improving health, enhancing experience of care, and reducing total costs of care.²⁴ While guidelines call for initiation of transition preparation by early adolescence,¹⁹ there is a lack of consensus about the optimal time to transition care²⁵ and a great deal of variability exists in clinical practice. We focus on youth aged 15 – 25 years, with the goal of encompassing the years surrounding transition to adulthood and transfer of care for the majority of youth in the U.S., while maintaining flexibility about the timing of transfer.

Solution

Model Design

Overview—We based the model design on a review and synthesis of clinical and health services research as well as observations of successful transition programs and high-performing healthcare systems⁶ (see Appendix 1). We first identified patients' and providers' unmet needs related to transition and then generated a model focused on addressing these needs utilizing high value care strategies. This project was determined to be exempt from review by the local Institutional Review Board.

Literature review—Our initial literature review focused on identification of cost-driving factors for AYA with chronic illness. A subsequent review examined evidence-based transition programs with impact on reducing utilization and/or costs. Where evidence from interventions with AYA populations was not available, we searched for interventions that reduce cost in adult chronic disease populations and/or during other types of transition (e.g. hospital to home).

Observation and interviews—Experts in the fields of transition and care coordination for complex patients nominated exemplar sites for observation and interview. We directly observed care at four clinical sites and conducted semi-structured interviews of patients, parents, staff, and providers. Two of these sites were state-of-the-art pediatric transition clinics: one staffed by medicine-pediatrics providers specializing in care of AYA with complex chronic illness in an academic setting and one with a multidisciplinary transition program within a pediatric transplant clinic. In addition, we observed pediatric primary and

*The American Academy of Family Physicians, the American College of Physicians, and the American Academy of Pediatrics

specialty care at one integrated health system known for providing exemplary high value care to children but which lacked a structured transition program. The fourth observation was at an “adjacent possible” site – a health plan delivering high value integrated care to high-risk seniors with chronic illness. We also conducted semi-structured interviews with providers in three additional types of transition delivery models: a consult service, in which the patient and family attend a clinic devoted to issues of transition while still receiving medical care from their usual primary and specialty care providers; a transition program embedded within a patient’s pediatric medical care; and a transition clinic to which patients transfer during adolescence to receive primary care until the age of 24. We interviewed clinicians providing care to adults in four different health systems in order to understand issues that receiving providers face after transfer. Finally, we spoke with a convenience sample of additional patients, parents, and advocacy groups with personal experiences in transition.

Synthesis of identified needs—We compiled a list of over 100 unmet needs and transition challenges from the literature review, site observations, and interviews. Three members of our team coded these needs into 10 themes (Figure 1, Appendix 2). Discrepancies were discussed among team members and resolved by consensus. The same team members then independently rated each theme in three equally weighted categories: the degree to which, based on existing evidence, addressing the need could influence: 1) clinical outcomes, 2) care experiences, and 3) cost of care. Twenty-five external stakeholders identified during literature review, observations and interviews used a 10-point Likert scale to rate each of the 10 major themes by degree to which addressing the area is important for high quality transition care and rank ordered the top 3 most important themes. Needs that emerged as highest priority are listed in Figure 1.

Model prototyping—We generated potential solutions for addressing high-priority needs with a focus on incorporating evidence-based interventions and high value care strategies to maximize health outcomes per dollar spent.²⁶ Proposed solutions were refined iteratively based on feedback from young adults with chronic illness, healthcare administrators, clinicians, and researchers with expertise in transition care and/or chronic disease management. This feedback was received informally as well as through a structured monthly review over a six month period.

A New Model of Transition Care

Three major categories of solutions were identified: building and supporting transition-specific self-management skills, engaging the receiving team, and guiding patients and families through the transition. Specific solutions proposed for accomplishing these tasks are summarized in Table 1.

Of central importance to the cost sustainability of the model is the assumption that not all patients will benefit from all proposed interventions. Therefore, the intervention relies on in-person assessment, augmented with standardized screening instruments to better match relevant transition interventions to patient and family needs. For example, universal screening would identify comorbid anxiety and depression, leading to referral for a more in-

depth assessment and treatment when indicated. Similarly, only a subset of AYA with high medical or psychosocial complexity will warrant direct involvement of a care manager or a face-to-face hand-off between pediatric and adult providers.

Building and Supporting Transition-Specific Self-Management Skills

Young adults transitioning from pediatric to adult-oriented care settings are expected to assume a more independent and active role in their healthcare, a challenge for which they are often not adequately prepared.^{27,28} Enhancing self-management ability ahead of transfer will better prepare AYA and their families to successfully enter the adult healthcare environment. In some cases, parents or caregivers must learn to gradually shift responsibility for disease management to the young person. In other cases, interventions may need to be directed to a caregiver, such as in patients with severe cognitive impairment.

Solution 1: Coaching for transition-specific self-management skills

Description: Self-management coaching incorporates motivational interviewing and skills transfer to enhance initiative, efficacy, and ability to manage chronic disease through times of transition. Patients and/or families work with trained layperson coaches to learn how to better manage their own transition by developing important communication, self-advocacy, and problem solving skills as well as managing stress. When appropriate, coaching emphasizes the development of these skills in the young adults while maintaining support from parents and peers. In settings where AYA are not anticipated to independently manage their care into the future, coaching focuses on caregivers. Patients and/or family members with low levels of self-efficacy and/or motivation for self-management are most likely to benefit from coaching and can be identified using assessments of patient activation.^{29–31}

Evidence-Base: Chronic disease management programs for older adults improve self-management skills using peer health coaches who focus on problem solving, decision-making, and confidence building.³² Participation in these programs is associated with improved health behaviors, self-efficacy,³³ and health status, as well as fewer visits to the emergency department.^{34,35} In addition, a number of health coaching interventions have shown positive outcomes for adolescents with specific conditions such as asthma³⁶ and type 1 diabetes.³⁷ A recent small study using technology-based coaching demonstrated improvement in health-related self-efficacy across multiple conditions among AYA, although it did not report on costs or the impact on utilization.³¹ Dedicated coaching or care management programs with a strong focus on building self-management skills have achieved cost savings of 3 to 14% primarily by decreasing avoidable hospitalizations and emergency room visits.^{38,39}

Solution 2: Online cognitive-behavioral therapy for anxiety and depression

Description: Patients are uniformly screened for anxiety and depression and offered timely access to treatment. One high value treatment option for patients with mild-to-moderate anxiety and/or depression is online cognitive behavioral therapy combined with brief weekly check-ins with a member of the care team. Primary caregivers also undergo screening and referral to online treatment, just as new mothers are routinely screened for post-partum depression within pediatrics.

Evidence-Base: Mental health comorbidities are associated with decreased adherence to medical regimens¹⁴ and increased medical expenditures.^{40,41} Psychological interventions for anxiety and depression are effective⁴² and have been shown to decrease medical costs, with the largest effects demonstrated for treatment integrated with medical care.¹⁵ Despite this, 66% of AYA with mental illness do not receive care.⁴³ Web-based cognitive behavioral therapy (CBT) is effective and feasible for treating mild-to-moderate anxiety and depression in young adults.⁴⁴ A study comparing face-to-face CBT with web-based CBT plus low-level therapist support showed comparable clinical outcomes and a 15% cost savings for online treatment.⁴⁵ Although online treatment has high dropout rates,⁴⁶ low intensity person-to-person contact enhances treatment completion.^{47,48} Emerging research suggests that the stronger effect of person-to-person contact is related more to enhancing motivation for completing treatment rather than the content of the person-to-person interaction itself.^{49,50} Depression among caregivers has been linked to worsened health outcomes and increased utilization for adolescents with some chronic illness.^{51,52} Web-based CBT is a feasible, low-cost option to address anxiety and depression amongst caregivers.

Engaging the Receiving Team: Many adult-oriented providers report discomfort treating young adults with serious childhood-onset chronic illness.^{53–56} This discomfort is exacerbated by the fact that the move to adult care is frequently unplanned – prompted by age-related changes in benefits or by the emergence of “adult” conditions such as hypertension or pregnancy. In these unplanned transfers, adult providers receive little background or guidance for caring for these complex patients. Routinely identifying, engaging, and communicating with receiving care teams in advance of – and during – care transfers will increase the likelihood that adult care teams have the information and guidance needed to safely care for these patients throughout the high-risk time of transition. This can also serve to build networks of providers within the adult health system and gradually enhance the capacity to deliver developmentally appropriate, high quality care.

Solution 3: Mobilize the receiving care team

Description: A transition team leader identifies and engages key providers in the receiving system early in transition planning. A patient-centered plan is established for collaboration between adult-oriented and pediatric providers to facilitate transfer of patients. This includes connecting community primary care providers with appropriate specialists (whether pediatric or adult), facilitating an efficient hand-off of information, and ensuring that communication occurs across care settings (e.g. hospital, outpatient care, emergency department). Support provided to the receiving team is greater for more complex patients. Where health systems have existing infrastructure for care management, the transition team leader will engage the adult care managers prior to transfer of care.

Evidence Base: In the Chronic Care Model, a clear division of labor is established for acute care versus planned management of chronic disease.⁵⁷ Interventions incorporating these tactics have positively impacted clinical outcomes and costs in older adults.⁵⁸ For children with chronic, complex illness, supporting primary care physicians with nurse practitioners decreased hospitalizations and emergency room visits and reduced medical costs by 50%.⁵⁹ Another program in which nurses coordinated care between primary care, specialty, and

inpatient providers and connected patients with community resources saw healthcare cost reductions of 26%.⁶⁰

Solution 4: Telemedicine specialty support for adult PCPs

Description: Specialty support via telemedicine enables adult primary care providers to consult with pediatric or adult specialists who have expertise in rare childhood-onset conditions. Consultations could be conducted using telephone, low-infrastructure video conferencing services, or other web-based platforms.

Evidence-Base: Weekly telephone consultation has been a feasible model for connecting rural primary care physicians to adult sub-specialists in a tertiary care center and has increased the confidence of primary care providers in treating unfamiliar conditions.⁶¹ Studies on the impact of this low-cost intervention on utilization and overall healthcare expenditures are ongoing.

Guiding Patients and Families Through the Transition: Age-related changes in insurance coverage^{66,67} as well as services such as education and durable medical equipment benefits are common during the time of transition. Such changes can make it more difficult to access appropriate care, resulting in important – even life sustaining – needs going unmet. Providing guidance to patients and families will minimize lapses in care and improve care experiences.

Solution 5: Guide services

Description: Each patient is linked with a patient guide who conducts assessments utilizing standardized instruments for anxiety, depression, activation/efficacy for chronic disease self-management, transition readiness, and medical and psychosocial complexity in order to direct AYA and families to appropriate services (e.g. social work, behavioral health, online CBT [Solution 2], coaching [Solution 1]). Guides use a transition checklist adapted from hospital to home⁶² and pediatric to adult care transition tools^{63–67} (see Appendix 3) and work with the patient and family to create customized, focused action plans and timelines for completion of all items. Guides also perform frequent, brief check-ins with AYA via text messaging to facilitate progress toward completion of tasks on the transition checklist and to update action plans. This also allows the guide to direct patients to additional services as a patient's status changes and to reduce loss to follow-up. For those tasks requiring input by other care team members (e.g. transfer medical summary from physician), guides provide templates and reminders to facilitate timely completion. Customized transition timelines allow for staggering transitions between different providers and services, making the process more gradual. Guides help to anticipate gaps in insurance coverage, services, or provider availability and problem solve regarding methods to bridge the gaps identified. Patient guides also work with patients to create and maintain a concise, up-to-date, portable medical summary using one of the many available smartphone applications or web-based programs (e.g. MyHealth Passport⁶⁸). Lastly, guides educate AYA and families to frame expectations for the transition period and remain as a point-of-contact for patients and families throughout the transition period.

Evidence-Base: During transition, help with simple tasks such as booking appointments and providing after-hours telephonic support decreased hospitalization by as much as one-third among young adults with type 1 diabetes, thereby reducing healthcare costs by one-third.⁶⁹ Another study in patients with type 1 diabetes found that the use of navigators reduced post-transfer healthcare dropout rates from 40% to 11%.⁷⁰ Interventions that include a structured transition program with a guide or a checklist have been associated with reductions in re-hospitalization and overall medical costs in adults transitioning from hospital to home.^{62,71,72} A program using trained low-cost peer guides in pediatric primary care resulted in reduced visit time with physicians in primary care and was judged to significantly decrease patient visits to the emergency room.⁷³ Several studies indicate high provider satisfaction and perceived usefulness of portable medical summaries.^{74,75}

Intervention Team: At the core of the Bridge Team is the patient guide who serves as the point-of-contact for each patient (solution 5). A health coach is involved with those patients who lack health self-management skills necessary for successful transition (Solution 1). A team leader (e.g. physician assistant, nurse practitioner, social worker, or registered nurse) oversees the program, focusing on mobilizing receiving providers (Solution 3), identifying telemedicine specialty support for PCPs when needed (Solution 4), and providing oversight and coordination support for the most complex patients.

Panel size will depend on the size and complexity (both medical and psychosocial) of the population being served and the infrastructure within the implementing health system. Training includes education on developmental needs of AYA and challenges faced by young adults with chronic illness transitioning to adult care. Motivational interviewing and problem solving training is also provided in order to effectively engage and empower AYA, families, and providers across both care systems.

Lessons for the Field

AYA with chronic illness experience challenges similar to other populations requiring transition care, such as patients transitioning from hospital to home or transitioning out of acute phases of illness (e.g. post-transplant or post- myocardial infarction). The 2001 Institute of Medicine report, “Crossing the Quality Chasm”, describes such transition as “layers of processes and handoffs that patients and families find bewildering and clinicians view as wasteful.”⁷⁶ Echoing ongoing work to improve these transitions^{62,71,77}, our model seeks to provide patients and caregivers with the skills needed to navigate changes in healthcare settings. However, unique features of “emerging adulthood”⁷⁹ call for an adapted approach to transition care with emphasis on the particular developmental needs of AYA, the shifting roles of parents and caregivers, and the treatment of comorbid anxiety and depression. Our proposed solutions build on and operationalize recommendations made within pediatric to adult care transition consensus statements, which include a call for uninterrupted, coordinated, developmentally appropriate care with the usage of a portable medical summary and structured transition plans.

Effective implementation of the model will be contingent on understanding and adapting to the unique features of the individual health system, local context and resources, and the

characteristics of the population being served.⁷⁸ Patient engagement and retention will be critically important to program success as young adulthood can be a particularly challenging time to engage young people and their families. Today's healthcare cost crisis makes it imperative that evaluation of this and other transition interventions include all domains of the triple aim. Health outcome measures will need to be tailored to each target population (e.g. frequency of avoidable hospitalizations in young adults with type 1 diabetes, rates of rejection in solid organ transplant recipients). Because transition to adult care is a prolonged process lasting up to several years, detecting measurable impact on clinical health outcomes will require an extended period of study and will necessitate measurement of commonly accepted intermediate outcomes such as activation for chronic disease self-management, transition readiness, and "successful transfer" (establishment of care as planned with adult-oriented providers). Further study is needed to confirm the association between these metrics and long-term health outcomes in AYA with chronic illness.

Unresolved Questions

While we focus on solutions that we believe will provide the highest value, we are limited in estimating the financial impact of our model due to the paucity of cost data available for this population. Studies measuring healthcare costs of young adults with chronic illness during the transition period are sorely needed as are studies to better inform the timing of transition and transfer interventions. We relied on evidence from studies conducted in populations of diverse age and diagnostic mix, in large part due to relative scarcity of evidence-based interventions specifically addressing transition for AYA with chronic illness. Important barriers such as alignment of financial incentives, insurance coverage, and medical education were outside of the scope of this work. However, strategies for addressing these barriers will also be important to improving outcomes during transition.

Despite these limitations, we believe that there is sufficient evidence to test this unique combination of solutions to assist young people with serious chronic illness to safely and economically transition from pediatric to adult-oriented healthcare. We are currently initiating pilot tests to evaluate the impact of this model on health and healthcare value.

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Appendix 1. Model design process

Appendix 2: Unmet transition needs identified during the needs assessment process

10 Categories of unmet transition needs	
1. Identify who needs to transition and when.	<p>Need a way to:</p> <ul style="list-style-type: none"> • Identify which patients should be kept within pediatrics and who should be transitioned to adult providers • Identify who is ready for transition • Perform executive functioning/cognitive functioning assessment • Administer transition-specific tools (asking what tasks patient “can” do vs. what patient has already done) • Segment teens by age or transition readiness for appropriate preparation • Identify appropriate age for transition preparation • Be more flexible with who and when to transfer • Make transition planning tailored to each patient and individualized
2. Improving communication	<p>Need a way to:</p> <ul style="list-style-type: none"> • Have better communication between pediatric and adult providers • Have providers communicate professionally so patients are not negatively affected • Make pediatric providers feel more confident in adult providers • Make adult providers feel more appreciated • Gradually introduce the adult clinic • Communicate with patients (What is patient’s preferred method of communication?) • Follow up without a patient physically coming to clinic • Have more functional communication between providers and patients • Teach AYA patients who, when and how to contact with health related problems • Effectively convey information to patients in order to assist in making treatment decisions • Have more direct communication prior to transition between pediatric and adult providers • Find a balance between multidisciplinary team benefit versus patient fatigue and sense of being overwhelmed • Direct attention towards long-term complications • Discuss long-term plans early on • Review and clarify treatment plan at end of each treatment visit • Promote relationship building between referring providers and subspecialists • Close the loop on treatment plans between patients and providers • Improve communication between subspecialists regarding long term disease management • Establish and prioritize goals for particular visits • Recognize and address impairments (e.g. hearing, vision, speech) • Reach and stay in touch with patients (What happens if a patient misses clinic?)
3. Improving care coordination	<p>Need a way to:</p> <ul style="list-style-type: none"> • Have more coordination of care • Find providers that are able to deliver coordinated care • Provide financial support for coordination of care • Find supportive personnel for care coordination

10 Categories of unmet transition needs
<ul style="list-style-type: none"> • Have continuity between inpatient and outpatient care • Have device and machine settings easily accessible • Have exam rooms suitable for lifts, wheelchairs, etc. • Have a physical space amenable to group discussions • Prevent avoidable emergency department visits • Dispose of medical equipment that is not being used • Provide necessary medical equipment to patients in a timely fashion • Use patient and caregiver time more efficiently in clinic • Address pain to keep patients out of the emergency department • Keep track of patient panel (population management) • Avoid unnecessary face-to-face clinic visits
<p>4. Focusing on patient and family, not the disease Need a way to:</p> <ul style="list-style-type: none"> • Have a more holistic, patient-focused approach, not disease focused • Address AYA issues such as sexual health and relationships • Improve patient's functional status • Have better and more clear goals of care discussions • Identify desirable patient outcomes when disease state is expected to deteriorate • Incorporate family perspective when setting outcome goals in cognitively impaired patients • Prevent patient burnout • Attend to palliative care issues • Instill hope about the future • Address the concerns of AYAs when they are different from provider's concerns
<p>5. Addressing mental and behavioral health Need a way to:</p> <ul style="list-style-type: none"> • Provide better mental health assessments • Provide better mental health treatment options • Make mental health services more accessible • Extend mental health services to caregivers
<p>6. Empowering the young adult Need a way to:</p> <ul style="list-style-type: none"> • Incorporate preferences of young adults into the medical system • Promote independence and develop a direct relationship between provider and the young person • Care for patients while they are in college or on a mission • Promote self-management skills • Have a formal assessment of patient engagement • Find balance between patient and family perspectives • Interact with more young people with similar medical conditions • Foster independence and gradual assumption of responsibility by teens • Promote peer support • Find patient advocates and patient navigators

10 Categories of unmet transition needs

7. Supporting the family

Need a way to:

- Help parents step back
- Provide respite care
- Prevent family/caregiver burnout
- Offer better support for parents during the transition
- Have balance between patient and family perspectives
- Support aging caregivers
- Incorporate caregivers after transition, including caregivers who may not be present at the appointment
- Address multiple family member's needs in the same setting
- Address fear of the unknown for parents
- Manage expectations for changes in medical care

8. Identifying appropriate providers

Need a way to:

- Build capacity within pediatrics to care for AYA
- Have adult providers be more comfortable caring for those with pediatric onset conditions
- Identify appropriate adult providers with an interest in caring for young adults
- Obtain consistent information about potential adult providers (for pediatricians)
- A way for adult providers to readily access information on management of childhood onset conditions
- Link to and support joint Internal Medicine/Pediatrics trained providers
- Reduce unnecessary subspecialist visits/ promote primary care management as possible
- Prevent provider burnout
- Have continuity of care during the initial transition
- Address the fear of the unknown on the adult side for pediatric providers
- Sustain social workers
- Capture and compensate non-RVU based work

9. Improving access to relevant medical information

Need a way to:

- Have online access to the medical summary
- Include information on durable medical equipment in the medical summary
- Have a medical summary include key information (contact information for clinic and patient, guidance on when to call for problems, diagnoses, list of medical problems, list of medications, all updated) rather than large volumes of unsynthesized records
- Prioritize problem list in the electronic medical records
- Have better access to medical records
- Decrease amount of paperwork

10. Addressing insurance changes

Need a way to:

- Anticipate and plan for upcoming changes in coverage and services
- Address a lack of appropriate insurance coverage
- Track costs of childhood illness over lifetime

Appendix 3: Transition checklist

Pre-Transfer checklist

- ☐ The young adult and family are aware of the upcoming need to transition to adult- oriented care
- ☐ The young adult and family have agreed on their respective roles in the patient's care going forward
- ☐ Potential insurance changes and their implications have been discussed
- ☐ The young adult and/or family has appropriate self-management capability including:
 - ☐ Activation and confidence for disease management
 - ☐ Knowledge: e.g. understanding of diagnosis, medications, treatment plan, understanding of what symptoms to watch out for & who to call if they arise, understanding of the impact of high risk behaviors on their health in the context of their chronic illness
 - ☐ Skills: Able to make appointments, fill prescriptions, communicate with the healthcare team, etc.
- ☐ Comorbid anxiety & depression are not present or, if present, the young adult is stable and receiving appropriate treatment
- ☐ The young adult has a concise & up-to-date complete medical summary including an active problem list, technology settings, medications, and plans for next steps of care
- ☐ Goals of care have been reviewed
- ☐ Pertinent legal issues have been addressed (e.g. guardianship, authorization for parents/others to have access to medical information, durable power of attorney)
- ☐ Other needs/services have been addressed (e.g. for help with ADLs, Durable Medical Equipment needs, education/vocational needs, housing, etc.)
- ☐ A plan is in place for obtaining adult-oriented primary care including:
 - ☐ If transfer to a new provider is needed:
 - ☐ An initial appointment has been scheduled
 - ☐ Information has been provided to the new provider
 - ☐ A warm handoff has been done if indicated
 - OR
 - ☐ The young adult will be continuing with his/her current primary care provider who is able to provide ongoing age-appropriate care
- ☐ A plan is in place for obtaining adult-oriented specialty care including:
 - ☐ If transfer to a new provider is needed:
 - ☐ An initial appointment has been scheduled
 - ☐ Information has been provided to the new provider
 - ☐ A warm handoff has been done if indicated
 - OR
 - ☐ The young adult will be continuing with his/her current specialty care provider who is able to provide ongoing age-appropriate care
- ☐ The young adult is medically stable
- ☐ The young adult is stable from a psychosocial standpoint
- ☐ **All of the young adult and family's questions & concerns have been addressed**

Post-transfer checklist

- ☐ The young adult is receiving developmentally appropriate, high quality care from an adult-oriented provider per guidelines for his/her condition
- ☐ The young adult/family is satisfied with their care post-transfer
- ☐ Updates on the young adult's status have been conveyed back to the pediatric team

Figure 1.

Needs assessment and systematization process

*Stakeholders included: young adult patients, families and caregivers, pediatric and adult providers, patient advocacy groups, and children's health foundations

Table 1

High value care during transition from pediatric to adult healthcare systems

	Challenges	Solution	Predicted Impact*
Building and supporting self-management	Tumultuous developmental period → decreased treatment adherence	Coaching for self-management	↑ treatment adherence ^{12,79,80} ↑ self-efficacy for disease management ^{34,35} ↑ health status ^{34,35} ↓ hospitalizations ³⁸ ↓ ED use ³⁵ ↓ health expenditures ^{38,39,81}
	Parents & young adults are unclear who is “in charge” of self-management		
	Parents may have difficulty stepping back from manager role when appropriate		
	Depression & anxiety are common, undertreated, and associated with decreased treatment adherence	Web-based cognitive behavioral therapy	↓ anxiety and depression ^{44,48,82} ↓ health expenditures ^{15†}
Engaging the receiving team	Care team composition and roles differ between pediatrics and adult medicine	Mobilize the receiving care team	↑ patient quality of life ⁵⁹ ↑ patient and family experience ⁵⁹ ↓ health expenditures ^{59,83}
	Appropriate adult providers can be challenging to locate		
	Typical primary care appointment timeslots inadequate for complex patients		
	Adult specialists may lack expertise in childhood conditions	Telemedicine specialty support for adult PCPs	↑ provider experience ⁶¹
	Pediatric providers are often anxious about sending patients to adult healthcare		
Guiding patients and families through the transition	Transition coincides with age-related service changes (e.g. insurance, PT, OT, durable medical equipment)	Patient guidance using a transition team and checklist	↓ hospitalizations ^{62,71,72,84} ↓ health expenditures ^{62,69,71,84} ↑ patient satisfaction ⁷¹ ↑ patient quality of life ⁷¹ ↑ clinical decision-making ⁷⁴ ↑ provider experience ^{74,75}
	No point-of-contact for health related crises		
	Important details of care are overlooked		
	New providers do not receive relevant patient history		

* Where available, research relevant to adolescents and/or young adults with chronic illness is cited. Where unavailable, literature from other populations is cited.

† Meta-analysis for in-person CBT