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Transition Care: Future Directions in Education, Health Policy, and Outcomes Research

Niraj Sharma, MD, MPH, Kitty O'Hare, MD, Richard C. Antonelli, MD, MS, and Gregory S. Sawicki, MD, MPH

Division of General Medicine, Department of Medicine, Brigham and Women's Hospital (Drs Sharma and O'Hare), Division of General Pediatrics, Department of Medicine, Boston Children's Hospital (Drs Sharma, O'Hare, and Antonelli), and Division of Respiratory Diseases, Department of Medicine, Boston Children's Hospital (Dr Sawicki), Boston, Mass

Abstract

All youth must transition from pediatric to adult-centered medical care. This process is especially difficult for youth with special health care needs. Many youth do not receive the age-appropriate medical care they need and are at risk during this vulnerable time. Previous research has identified barriers that may prevent effective transition, and protocols have been developed to improve the process. Health outcomes related to successful transition have yet to be fully defined.

Health care transition can also be influenced by education of providers, but there are gaps in medical education at the undergraduate, graduate, and postgraduate levels. Current changes in federal health policy allow improved health care coverage, provide some new financial incentives, and test new structures for transitional care, including the evolution of accountable care organizations (ACO). Future work must test how these systems changes will affect quality of care. Finally, transition protocols exist in various medical subspecialties; however, national survey results show no improvement in transition readiness, and there are no consistent measures of what constitutes transition success.

In order to advance the field of transition, research must be done to integrate transition curricula at the undergraduate, graduate, and postgraduate levels; to provide advance financial incentives and pilot the ACO model in centers providing care to youth during transition; to define outcome measures of importance to transition; and to study the effectiveness of current transition tools on improving these outcomes.

Keywords

health care financing; health policy; medical education; outcomes research; transition; youth with special health care needs

The transition from pediatric- to adult-focused health care for adolescents with chronic conditions is a growing phenomenon. It is estimated that about 10 million youth aged 0 to 17 years in the United States have special health care needs. The proportion of children with special needs increases with age; about 9% of children under age 6 have special health needs, but this proportion almost doubles, to about 17%, for those aged 12 to 17 years.¹ Today, 90% of children with chronic conditions survive into adulthood, and in the United States alone, 500,000 youth with special health care needs (YSHCN) reach age 18 each year.² This large number of YSHCN is a result of advances in treatments, pharmacology, surgical techniques, medical technology, and health care delivery systems that have been made over the last 3 decades.³ Unfortunately, upon reaching adulthood, many of these patients do not receive age-appropriate medical care.⁴ The goal of a successful transition is for a young adult to successfully establish care in a new adult medical home from which a new continuity relationship can be established.

It is broadly acknowledged that the process of preparing YSHCN for the eventual move to adult-focused health systems should start in early adolescence and should involve individualized planning and ongoing skills development.¹ A recent consensus statement of the American Academy of Pediatrics (AAP), the American Academy of Family Physicians (AAFP), and the American College of Physicians (ACP) suggests that this process should be initiated by age 12. A major goal of transition preparation should be to improve self-management skills in anticipation of eventual transfer of care. YSHCN that receive care from some medical specialists, such as internal medicine–pediatrics (med-peds) and family medicine, may not require the actual transfer of their primary care to another provider. However, even such medical practices should implement policies to encourage YSHCN to learn self-management skills and take on more developmentally appropriate responsibility as they get older. Although some systems advocate a particular age as the appropriate time for transfer, it is increasingly clear that developmental readiness, regardless of age, is a better indicator for the timing of transfer.

The transition to adult care is often disorganized as result of barriers, including emotional and cognitive developmental challenges, lack of individual and family-centered social supports, difficulties in communication and coordination of care between pediatric and adult health care systems, and gaps in health insurance at the age of transition.⁵ Programs are being established to address many of these barriers,⁶ but additional work needs to be done.

The process of moving from pediatric to adult care can be influenced by early education of patients, families, caregivers, and health care providers. In addition, health care policies must be developed and promoted which support the unique needs of this population. As with any quality improvement effort, valid measurement strategies must be developed to guide transformation of care delivery. Key questions for this field include how to define successful transition, how to develop health utilization and patient-related outcome measures for transition, and ultimately whether successful transition improves young adult health outcomes.⁷

This article reviews the current state of transition care and proposes recommendations for future directions in transition care provider education, health care policy and clinical work, and outcomes research.

Medical Education and Transition

In joint consensus statements, the AAP, AAFP, and ACP have twice set goals that “all physicians who provide primary or subspecialty care to young people with special health care needs 1) understand the rationale for transition from child-oriented to adult-oriented health care; 2) have the knowledge and skills to facilitate that process; and 3) know if, how, and when transfer of care is indicated.”^{1,6} Despite the increasing number of YSHCN, there remains inconsistent training in transition issues at all levels: undergraduate medical education (UME), graduate medical education (GME), and maintenance of certification (MOC) (Table 1). Multiple groups, from the federal government to professional societies, have called for increased training for all providers in the transition to adulthood.^{1,8}

Data from focus groups demonstrate that although training in chronic disease is important to providers, patients, and families, it is not adequately addressed during residency.⁹ Recent graduates of pediatric residency programs cite gaps in training regarding chronic disease management.¹⁰ Further, 33% of programs did not provide any education about the transition from pediatric to adult care.¹¹ Although the Accreditation Council for Graduate Medical Education Next Accreditation System (NAS) Common Program Requirements refers to competencies in “transition,” this is regarding the transfer of patients from different levels of care and team handoffs, not specifically YSHCN.¹²

Internists are much more likely than pediatricians to report training as a factor limiting their ability to care for young adults with childhood-onset chronic disease, particularly patients with neurodevelopmental disorders.^{13,14} Internists report a lack of training in congenital and childhood-onset conditions as a major barrier in their willingness to accept youth with chronic disease into their practices.¹⁵ One study of physicians in practice showed that 96% of pediatricians reported treating a patient with cystic fibrosis in residency, while only 78% of internists reported similar experience in their residency training. Within this cohort, 38% of pediatricians felt comfortable being the primary care physician for a patient with cystic fibrosis, while only 15% of internists felt the same. By comparison, 91% of internists felt comfortable being the primary care physician for a patient with hypertension.¹⁶ Med-peds trainees report comfort caring for YSHCN, with 86% of med-peds residents reporting good or excellent preparation to care for YSHCN.¹⁷ However, to date, there are fewer than 400 graduates of med-peds residency programs annually, so med-peds cannot be the only solution to the problem of complex care for young adults.¹⁸

There are specific recommendations that should be implemented at each level of medical training to teach about transition (Table 2). YSHCN and their families should be included to develop content and as faculty to utilize their expertise and support authentic youth engagement. The Institute of Medicine has recommended increased training of all levels of health providers in adolescent medicine, including the transition to adulthood.¹⁹ At the UME level, curricula must be adjusted to recognize that individuals with particular diseases not

only survive into adulthood but also face additional challenges as they grow older. As part of their education in health policy and health care systems, medical students should be taught about care handoffs, disease management, and other points around transitioning to adulthood. These skills should be included in the content and testing for the United States Medical Licensing Examination. Teaching these concepts to medical students while they are undifferentiated in their choice of specialty will prepare them to care for YSHCN regardless of their future field.

Within GME, there should be a natural shift toward learning to provide care for these long-term survivors. Each specialty should include requirements for training with YSHCN that are based on the competencies. For example, within the medical knowledge competency, an orthopedic surgery resident should learn about long-term management of patients with spina bifida. A pediatrics resident should gain exposure to chronic disease management within the ambulatory care setting as part of the practice-based learning and improvement competency. Finally, an internal medicine resident can learn about professionalism when learning how to speak to YSHCN who come to appointments with caregivers. Residents should also learn about transition planning. For example, family medicine residents should be taught to assess for self-management skills with their patients. Pediatrics and internal medicine residents should learn how to conduct an appropriate transfer of care modeled after the National Health Care Transition Center (NHCTC) 6 core elements of transition.²⁰ The NAS Milestones Project provides an excellent opportunity to assess residents' progress in learning about this topic.¹² It will specifically require program directors to develop entrustable professional activities within each competency to measure whether a resident is gaining the knowledge and skills related to transition. Questions about chronic disease and disability should also be included on licensure examinations, intraining examinations, and board examinations.

At the subspecialty level, there is a need for enhanced training in transition care for clinical fellows.⁸ A case in point: the majority of patients living with congenital heart disease are now over the age of 18 years.²¹ As a result, there is growing need for cardiologists trained in the complications of congenital disease in adults.²² Some pediatric cardiology fellowships are beginning to address this challenge by adding an additional optional year of training in adult congenital heart disease.¹² For medped residency program graduates, there are a handful of combined fellowship programs that emphasize continuous care through the life span, including rheumatology and nephrology. Many other subspecialty programs have similar needs, such as cystic fibrosis, pediatric hematology/ oncology, type 1 diabetes, and sickle cell disease. However, insufficient numbers of subspecialty programs have made explicit changes in their training to meet the growing need for transition care. All subspecialties should follow the lead of cardiology to include care of YSHCN as part of their core training.

Medical knowledge competencies in chronic disease and disability as well as transition care should be expected of physicians already in practice. Adult providers may have learned about survivable conditions such as acute lymphoblastic leukemia in medical school, but may be unfamiliar with the care for or long-term follow-up of these patients. Although continuing medical education (CME) may help motivated providers, educating all

physicians will require involving the medical specialty boards. The American Board of Pediatrics instructions for MOC already include specific competencies in the transition to adulthood; however, the American Board of Internal Medicine instructions do not.^{23,24}

Additionally, providers need training on how to best prepare patients for transition from pediatrics and integrate them into adult practices. The NHCTC has established the 6 core elements of transition for both pediatricians and adult providers.²⁰ Learning collaboratives, such as Got Transition, have also worked with individual practices and health systems to establish transition protocols.²⁰ There is clearly a need for broader dissemination by developing transition practice improvement modules for MOC and by developing more CME programs across all specialties.

Facility in transition care is not for physicians alone. Registered nurses, nurse practitioners, physician's assistants, clinical psychologists, social workers, and other allied health professionals play a role on the transition care team. In some settings, social workers or psychologists may perform a standardized transition assessment. Often nurses have much more sustained patient contact than do physicians, resulting in additional insight into transition needs and more opportunities for counseling. Transition care should be incorporated into curricula in all areas of the medical field.^{25,26}

Opportunity to Transform Systems of Care: Health Policy and Transition

It is generally agreed that the triple aim of the US health care system is to improve the experience of care, improve the health of populations, and reduce per-capita costs of health care.²⁷ These same health policy issues are seen with transition.

Among the many challenges to health care transition for YSHCN are administrative barriers (eg, transfer of medical records) and health system barriers (eg, health insurance). Although the percentage of YSHCN who are uninsured has decreased from 11% in 2002 to 3.5% in 2010, 34.3% of YSHCN do not have adequate insurance to meet their needs.²⁸ The Patient Protection and Affordable Care Act (ACA) of 2010 addresses the insurance coverage of this population by extending and mandating certain benefits (Table 3).²⁹

There are specific policy and financing recommendations that would benefit those undergoing transition (Table 4). At this point, the essential health benefits remain 10 broad areas, and the details of the coverage must still be specified. It is unclear how the Secretary of Health and Human Services will weigh the finances of each of the areas to equitably benefit all Americans. Although these health services are a step in providing needed care to youth and young adults undergoing transition, services, such as chronic disease management, must include the transition population.

The Supreme Court upheld the ACA in 2012; however, this decision is tempered by the decision on Medicaid expansion.³⁰ The Supreme Court concluded that it was unconstitutional to withhold all Medicaid funding to a state if it did not expand Medicaid to all nonelderly adults with household incomes about one-third more than the federal poverty line. Instead, it allowed states the option of expanding Medicaid, which many states have elected not to do. The court decision only focused on expansion; therefore, other portions of

the law, such as the essential health benefits, remain in place.³¹ The result of this decision will likely lead to variation in coverage and benefits between states that will further expose gaps in care that YSHCN already experience. This could also demonstrate potential disparity between those with Medicaid and others who are commercially insured. These individuals undergoing transition face a number of obstacles that can affect obtaining employer-based health insurance, such as unemployment or underemployment resulting from their chronic medical condition. Ensuring that all states expand Medicaid as promulgated by the ACA will mitigate some of the risk that transitioning youth face as they age out of their parental insurance coverage.

The passage of the ACA also establishes new financial models that foster improved coordinated care for transition. In particular, the evolution of accountable care organizations (ACO) presents an opportunity to address the needs of this population. Foundational to this model is the patient- and family-centered medical home provider, who serves as the central link between the patient, subspecialists, hospitals, and community-based agencies. Depending on the needs of the patient, and the resources in a given community, the medical home provider may be a primary care or subspecialty clinician. The medical home provider must be able to facilitate team-based care, in which the youth/family, subspecialists, and allied health professionals function as collaborators. Also critical to this model is an explicit commitment to proactive mechanisms of care coordination, ensuring alignment and integration of care delivery across all providers.

An important element of ACO design is the implementation of financing models that support the provision of care integration services across providers. These financing models offer the potential to promote and enable the activities of care coordination across settings and providers. These measurement frameworks are gaining increased attention and will serve as a key resource both for the provision of services as well as the measurement of outcomes for which systems will be accountable.³²

A key strategic opportunity for optimizing care outcomes for YSHCN is their identification as a population in need of integrated services. A recent study found that young adults with sickle cell disease, aged 18 to 30 years, have the highest rate of emergency department utilization as well as the highest rate of rehospitalization.³³ These baseline data provide a benchmark against which we can measure the effectiveness of care coordination across providers in an accountable care system.

The results of ACO pilots have been promising. One study comparing a group of patients in an ACO model compared to a control group showed a smaller increase in average spending per enrollee and an improvement in performance on measures of the quality of the management of chronic conditions in adults and of pediatric care. The ACO was allowed to share in these savings through the lower costs and the high quality of care provided.³⁴ Comparing various national ACO models prospectively will determine best practices in the future.

One of the hurdles that needs to be addressed is the question of how to measure quality in the transitional care of YSHCN. In the Medicare population, there are defined measures and

benchmarks for many conditions—for example, a target hemoglobin A1c level for patients with diabetes, or a target blood pressure for patients with hypertension. With respect to youth undergoing transition, the measures currently focus on process rather than outcomes. For example, in the annual survey of YSHCN, participants are asked whether “the youth’s doctor has discussed each of the following with him or her: a) transitioning to doctors who treat adults; b) changing health needs as youth becomes an adult; and, c) how to maintain health insurance as an adult.”²⁸ Although these are important process measures of transition, they do not offer any measure of health benefit or cost savings that would benefit physician groups that would establish an ACO for this population.

Beyond care coordination, financial payments and incentives may also assist in providing transition services. In March 2013, the Centers for Medicare and Medicaid Services (CMS) established new transitional care management CPT codes for billing. These new codes are specifically designed for a physician or qualified provider to follow-up with a patient within 30 days of a discharge from a hospital or similar facility.³⁵ These new codes will minimally assist with YSHCN, but it can serve as a model for CMS to include additional transition services. As an example, allowing pediatric and adult providers to bill simultaneously for visits during a specific time while a YSHCN is transitioning may assist in easing this process and increasing the likelihood of a successful transfer of care. Transition services billing should specifically be included in ICD-10.

Meaningful use (MU) can also serve as a model for how medical practices can be financially incentivized to build transition protocols into their care delivery.³⁶ As part of stage 1 MU, CMS has given practices financial incentives to utilize electronic health record (EHR) technology and track clinical quality measures. The clinical quality measures are built into the EHR as a way for practices to track the quality of care provided, and practices are financially rewarded by CMS for compliance.

Stage 2 MU expands on the core objectives and includes requirements that benefit YSHCN who are transitioning. These include providing clinical summaries for patients at each visit, generating lists of patients by specific condition to use for quality improvement or outreach, and providing a summary of care for each transition of care or referral. Stage 2 MU also requires practices to report on 9 out of a list of 64 clinical quality measures that fall into the following domains: Patient and Family Engagement, Patient Safety, Care Coordination, Population/Public Health, Efficient Use of Healthcare Resources, and Clinical Process/Effectiveness. However, transition care measures are not included in this list. Building transition quality measures and transition services, such as the 2011 AAP clinical report on transitions,⁶ into EHRs through future stages of MU will likely assist the transition process. Ultimately, this will also allow data to be collected that can be analyzed to measure the cost savings and health outcomes associated with these transition protocols. These policy recommendations, from fully establishing the ACA and ACO to refining recent changes in health care financing, will ultimately aid in the transition of YSHCN.

Outcomes Research in Health Care Transition: An Emerging NEED

Building on policy changes requires outcomes measures to assess the quality and finances associated with transition and ultimately align them with the triple aim of health care.²⁷ The increasing demand for transition services, particularly for youth with chronic medical conditions, creates a need to conduct rigorous outcomes research in order to foster transition program development and evaluation. The goals of transition care are to adequately prepare youth and caregivers for transfer by improving self-management skills and developing care plans. An additional goal is to train health care professionals to provide developmentally appropriate, continuous health care to YSHCN. However, a vast distance remains between these stated goals of transitional care and the demonstration that meeting these goals leads to improved health outcomes⁶ and studies establishing best practices are lacking.³⁷ Outcomes for transition need to be evaluated across the spectrum of age and care delivery systems, focusing on measures of transition preparation, transfer of care, and intake to an adult-oriented health system.

At an individual level, successful transition would include evidence of uninterrupted access to health care services, achievement of developmentally appropriate milestones, and maintenance of condition-specific health outcomes. These measures in part could be derived from administrative data evaluating gaps in care, presence of unscheduled utilization, or rates of hospitalizations or emergency department visits. However, other measures of successful transition would need to be obtained directly from patients and caregivers and therefore necessitate patient-oriented survey methods. At the present time, such surveys only assess very basic pretransition milestones.

Data from the 2001 National Survey of Children with Special Health Care Needs (NS-CSHCN) showed that less than 50% of parents of YSHCN reported having discussed transition with their adolescent's physician,⁵ and only 30% had a plan for addressing transition needs. Additionally, data from the 2005 NS-CSHCN identified variable state-level performance on a Maternal and Child Health Bureau transition services quality metric (a composite of 4 aspects of care aimed at supporting health care transition); the survey found that the presence of a medical home, and provision of adequate health insurance predicted an individual state's performance.³⁸ Subsequent analysis of the 2007 national Survey of Adult Transition and Health found that just over half of youth ages 19 to 23 years reported receiving counseling around transition, with greater rates of transition counseling identified in youth reporting good communication with health providers.^{39,40} Socioeconomic, racial, and ethnic disparities have also been recently documented in the receipt of transition services.⁴¹ Taken together, these national data suggest that many youth, regardless of disease severity, are not receiving anticipatory guidance to support transition to adult care from their pediatric health care providers, and as a result, transition support may be lacking. Youth may therefore be transitioning out of pediatric care without appropriate follow-up, or they may transfer from pediatric-centered health systems without the skills and knowledge needed to succeed in an adult-oriented system.³ Successful transition for individuals may include surrogates for skill, such as maintenance of insurance, avoidance of delays in care, and emergency room utilization.

Research evaluating clinician, parent, and youth perspectives on transition in select patient populations has been conducted in diverse patient populations, including cystic fibrosis,⁴² congenital heart disease,⁴³ diabetes,⁴⁴ HIV,⁴⁵ inflammatory bowel disease, mental health conditions,⁴⁶ rheumatologic disease,⁴⁷ and neuromuscular disease.^{46,48} In response, a number of clinical programs have been developed,⁴⁹ and transition protocols are also being tested nationally for feasibility.²⁰ Condition-specific data echo the national data showing lack of consistency with transition planning, processes, and outcomes. Although many clinical programs promote the acquisition of transition skills, it appears that these programs do not include measured assessments of transition readiness as part of routine care.⁵⁰ For example, a survey of cystic fibrosis care centers found that less than half consistently performed transition readiness assessments, and less than 20% had programs to foster the skills and knowledge needed for transition.⁵¹ Another theme that has emerged in condition-specific literature is the need to focus on health systems factors that could facilitate health care transition, such as provision of patient/family education and health care provider training, skills, and knowledge.⁵² Table 5 presents some potential transition outcome measures at the patient/family, health care provider, and health system levels. These measures can be utilized in a prospective fashion to guide the development of best practices.

One impediment to the incorporation of transition readiness skill development into research and clinical practice is the paucity of data on any validated, patient-centered instrument to assess youths' transition readiness skills. Transition readiness scales such as the Transition Readiness Assessment Questionnaire (TRAQ) have recently been developed and may facilitate comparative research on health care transition readiness and preparation.⁵³ The TRAQ is a skills-focused tool assessing the developmental process of health care transition readiness. Initial TRAQ validation demonstrated differences in age and gender, and recent evaluation suggests that higher TRAQ scores are associated with self-reported improvements in health care transition processes. Instruments such as the TRAQ need to be further studied as potential longitudinal measures of transition skills.

Despite the focus on transition planning, there are few data linking transition readiness and skills with improved adult health outcomes. Failures of transition services to the adult-centered medical system have been described, including a report of high rates of emergency care utilization among adults ages 20 to 29 in the United States,⁵⁴ as well as high rates of pediatric hospitalizations for young adults with chronic conditions.⁵⁵ A recent study of young adults with diabetes found that over a third reported a gap in care lasting over 6 months after transfer from pediatric care.⁵⁶ Only a small number of studies, all conducted in diabetic populations, have demonstrated that specific transition interventions improved disease-specific health outcomes.⁵⁷ Future research needs to focus on developing and validating outcome measures for the transition process, the ultimate transfer of care, and the establishment of care in an adult-centered medical home.

Outcomes research in transition continues to evolve. Incorporating health information technology, such as personally controlled health records, to the study of transition outcomes will likely benefit clinicians, researchers, and policy makers.⁵⁸ Priorities for future research should include measuring transition readiness and skills, transfer-of-care processes, and posttransfer health outcomes. Ultimately, such research will determine whether successful

transition processes and paradigms lead to beneficial improvements in health status and achievement of the triple aim of health care.²⁷ These results can drive future changes in medical education, health policy, and financing.

Conclusions and Future Directions

As the number of YSHCN has increased, the need to successfully transition these individuals to adult practices has become more apparent. Position statements by the leading primary care organizations in 2002 and 2011 are a step toward addressing this need. Previous research has described the barriers to transition faced by patients, families, and providers. Clinical programs and processes are also being developed. This foundational work needs to be built on in several areas.

Medical education at all levels must adjust in parallel to match the changing population needs. Policy changes are being implemented to address health insurance issues faced by patients undergoing transition. Furthermore, the evolution of financing models for delivery of coordinated, integrated care may enable alignment of accountability for outcomes across providers. Changes at the practice level are forthcoming with the development of ACO and care coordination. Future research must be done to assess whether the clinical protocols that are being developed actually have a long-term impact in the improvement of care for these patients. This is an opportunity to increase the measured quality of care while balancing the cost of care. In order to advance the field, medical educators must: integrate curricula on transition at the undergraduate, graduate, and postgraduate levels; support training of providers in patient-centered and team-based care; and provide standardized assessment in transition skills and knowledge via medical licensure exams, board exams, and maintenance of certification. Further, policy makers must include transition models of care in ACO pilots in centers providing care to youth and compare them prospectively for outcome measures and costs of care as well as develop financial incentives for providers to integrate transition services into their practices. Finally, outcome measures of importance to transitioning YSHCN must be defined, and the effectiveness of current transition tools on improving these outcomes must be studied.

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What'S New

Directions for future efforts in health care transition ought to do the following: integrate transition curricula at all levels of medical education; ensure that essential health benefits and future financial incentives include transition; include transition in accountable care organization pilots; define transition outcomes measures; and study the effectiveness of current transition tools.

Table 1**Medical Education Training Requirements**

Level of Training	Adolescent Medicine	Care Handoffs	Complex Care/Chronic Disease Management	Transition to Adulthood
UME ⁵⁹	Exposure	Yes	No	No
GME ¹²				
Peds	1 mo	Yes	Yes	No
IM	Exposure	Yes	Yes	No
Med-Peds	1 mo	Yes	Yes	No
FM	Exposure	Yes	Yes	No
MOC				
Peds ²³	Yes	No	Yes	Yes
IM ²⁴	Yes	No	No	No
FM ⁶⁰	Yes	No	Yes	No

UME = undergraduate medical education; GME = graduate medical education; MOC = maintenance of certification; Peds = pediatrics; IM = internal medicine; Med-Peds = internal medicine–pediatrics; FM = family medicine.

Table 2**Recommendations in Medical Education to Aid in Transition**

-
- Development of transition curricula at all levels of medical training.
 - For UME, include teaching on the long-term survival of diseases.
 - For GME, residents and fellows must learn to care for long-term survivors and about transition processes.
 - For MOC, practicing physicians should learn how to implement care for these patients into their practices, such as utilizing the NHCTC 6 core elements.
 - Expand training in these areas to other providers, including nurses and physician assistants.
 - Include YSHCN and families as subject matter experts and faculty for this content to support authentic youth engagement.
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UME = undergraduate medical education; GME = graduate medical education; MOC = maintenance of certification; NHCTC = National Health Care Transition Center; YSHCN = youth with special health care needs.

Table 3**Patient Protection and Affordable Care Act (ACA) of 2010 and Transition Benefits²⁹****Patient Protections**

- Prohibits private insurance companies from denying coverage to children under age 19 based on a preexisting condition.
- Guaranteed issue and guaranteed renewal.
- Prohibits rescission of coverage.
- Removes the annual and lifetime benefit caps for children and adults.
- Extends coverage of young adults on their parent's policy to age 26.
- Medicaid coverage expansion—eligibility up to 133% of FPL optional to states).
- Continuation of Medicaid coverage of former foster care children until age 26.
- Maintain current eligibility criteria and enrollment procedures for Medicaid and CHIP.
- Provide essential health benefits (beginning in 2014), detailed below.
- Essential Health Benefits
 - Ambulatory patient services.
 - Emergency services.
 - Hospitalization.
 - Maternity and newborn care.
 - Mental health and substance abuse disorder services.
 - Prescription drugs.
 - Rehabilitative and habilitative services and devices.
 - Laboratory services.
 - Preventative and wellness services, and chronic disease management.
 - Pediatric services, including oral and vision care.

FPL = federal poverty level; CHIP = Children's Health Insurance Program.

Table 4**Policy and Financing Recommendations for Transition**

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- Ensure that essential health benefits are weighted to include transition services.*
 - Expand Medicaid under the ACA to all 50 states.
 - Require that ACO include specific care coordination activities to support transition.
 - Compare ACO prospectively.
 - Establish transition quality measures.
 - Include transition for billing in ICD-10.
 - Allow for simultaneous pediatric and adult visits and billing during care transfer.
 - Financially incentivize providers for transition services.
 - Expand meaningful use to include transition quality measures.
 - Measure cost savings for practices that implement transition protocols.
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ACA = Affordable Care Act; ACO = accountable care organizations.

* Essential health benefits are listed in Table 3.

Table 5

Recommended Outcome Measures to Assess Health Care Transition

Stage of Health Care Transition	Domain		
	Patient/Family	Health Care Provider	Health System
Preparation	<ul style="list-style-type: none"> • Transition readiness • Quality of life • Transition knowledge • Health care utilization • Condition-specific outcomes 	<ul style="list-style-type: none"> • Use of transition care plan • Assessment of patient readiness • Patient/family education and counseling 	<ul style="list-style-type: none"> • Development of transition policy • Care coordination
Transfer of care	<ul style="list-style-type: none"> • Gap in medical care • Loss of health insurance 	<ul style="list-style-type: none"> • Preparation of patient summary • Communication 	<ul style="list-style-type: none"> • Use of patient summary • Communication between pediatric–adult systems
After transfer	<ul style="list-style-type: none"> • Health care utilization • Quality of life • Condition-specific outcomes • Health coverage measures 	<ul style="list-style-type: none"> • Intake policy for transitioning patients 	<ul style="list-style-type: none"> • Quality of intake to adult care • Care coordination • Financial costs and savings