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**Pediatric to Adult Health Care Transition:  
A Quality Improvement Project for Primary Care**

Nicole Jones

University of Massachusetts, Amherst

College of Nursing

DNP Project Chair: Constance Flynn, DNP, ANP-BC, FNP-BC, CARN-AP

DNP Project Mentor: Ami Bhatt, MD, FACC

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## Abstract

**Background:** With advances in pediatric care, the number of patients surviving into adulthood with chronic conditions has drastically increased, intensifying the complexity of the process of transition from pediatric to adult centered health care. Despite expert recommendations, established evidence reveals that overall transition outcomes in patients remain suboptimal.

**Purpose:** The aim of this project was to provide pediatric primary care providers (PCPs) with current evidence and professional practice recommendations in regard to systematic approaches for the transition of care to the adult setting.

**Methods:** This quality improvement (QI) project included the development of a provider toolkit based on best practice guidelines. The toolkit was presented to eight providers at one primary care practice with the intention of providing patient/provider resources as well as a framework to streamline the transition process for adolescents and young adults. Pre and post intervention surveys were administered to evaluate PCP confidence in engaging in discussions regarding transition planning for patients and/or their families, age at which discussions commence and interest in utilizing elements of the toolkit in clinical practice.

**Outcomes/Discussion:** Statistical analysis of the results demonstrated the educational intervention moderately impacted provider confidence in engaging in conversations with patients and/or their parents about transition planning. A statistically significant difference ( $p = 0.020$ ) was noted after the intervention in regard to age at which providers plan to begin to discuss transition planning with their patients. Providers reported they learned concepts about transition, would recommend the toolkit to their colleagues, and plan to pilot elements of the toolkit in future practice.

**Conclusion:** The intervention was well received, and project results revealed the potential success of implementing a structured approach from pediatric to adult health care in the primary care setting.

**Keywords:** health care transition, pediatrics, adolescents, youth, young adults, health care services, primary care.

## Introduction

For more than two decades, professional health organizations and public health agencies have recognized that the transition from pediatric to adult care is a priority to ensure lifelong positive health outcomes. With medical and surgical advances in pediatric care, the number of patients surviving to adulthood with chronic conditions has drastically increased, intensifying the complexity and importance of this process. The prevalence of adolescents and young adults between the age of 12 – 18 years with special health care needs (SHCN) is approximately 18.4% (Castillo & Kitos, 2017). Children with SHCN are individuals who have or are at increased risk of developing a chronic physical, developmental, behavioral, or emotional condition or require health related services of a type or amount beyond the typical pediatric requirement (McPherson et al., 1998). These SHCN include asthma, attention deficit disorder, autism, cystic fibrosis, depression, diabetes, Down syndrome, congenital heart defects, and sickle cell disease.

Despite expert recommendations, established evidence reveals that overall, transition outcomes in patients have been suboptimal, particularly among ethnic minorities (Sable et al., 2011). According to the 2016 National Survey of Children's Health, only 17% of youth with SHCN and 14% of youth without SHCN reported receiving transition planning support from their health care clinicians (Lebrun-Harris et al., 2018). The results highlight a gap in clinical practice and an opportunity for health care providers to implement successful transition processes.

## **Background**

Health care transition (HCT) refers to the purposeful, planned process that addresses the needs of young adults as they move from a child/family-centered care to adult/patient-oriented health care system (Blum, 2002). The ultimate goal of HCT is to optimize the quality of life and ability of young adults to independently manage their own health care by providing uninterrupted patient-centered healthcare. Formal transition planning should include age-appropriate education about medical conditions and promote skills in communication, decision making, self-care and self-advocacy (Sable et al., 2011).

Position statements by leading primary care organizations, including the American Academy of Pediatrics (AAP), American Academy of Family Physicians (AAFP), American College of Physicians (ACP) in 2002 and 2011, recommend that the transition from pediatric to adult care should begin at 12 years of age and become a part of routine primary and specialty care. A well-executed transition process takes place over a period of time where the burden of responsibility of health care management is gradually shifted from the parents/caregivers to the patient.

The concept of transfer refers to the actual point in time when the responsibility for patient care moves from one health care team to another. A well-timed transfer from pediatric to adult-oriented health care is specific to each individual but ideally occurs between the ages of 18 and 21 years. This is recognized as a vulnerable time period for young adults with SHCN as it coincides with many other significant life events such as entering college, moving away from home, launching a career, and becoming legally responsible for personal decisions.

Positive outcomes for young adults with SHCN as a result of a structured transition process include improvement in adherence to care, quality of life, and self-reported

health, increase in satisfaction with providers, reduction of barriers to care, a decrease in time between last pediatric and first adult visit, increase in adult ambulatory visits, and decrease in hospital admissions (Gabriel et al., 2017).

### **Problem Statement**

Young adults (ages 18 to 21 years) with SHCN are at risk for serious health sequelae as a result of multiple barriers and challenges which delay their transition and transfer from the pediatric to adult healthcare setting. Although successful transitions are recognized as critical for improving adult outcomes and reducing health care utilization and cost, an educational gap in health care transitions for primary care providers (PCP) persists. Recognizing the need for improvements in continuity of care from the pediatric to the adult setting, it was hypothesized that a quality improvement (QI) project at a pediatric primary care office could address this gap in practice. An educational intervention that would include the presentation of provider toolkit with access to reputable guidelines and recommendations was proposed and approved. The QI project focused on identifying patients appropriate for transition and increasing provider confidence in engaging in conversations about transition with patients and families about shared goals.

### **Review of the Literature**

A comprehensive search of literature was performed for transitional care utilizing the following databases: Cumulative Index to Nursing (CINAHL), PsycINFO, PubMed and Google Scholar. The review sought to identify the challenges of transition care among young adults as well as to provide evidence-based solutions to facilitate successful transitions. The search included controlled vocabulary and free text synonyms for the following concepts: “health care transition”, “health care services”, “pediatrics”, “adolescent”, “young adult”, and “primary care”.

Search parameters were limited to include full text publications from the years 2015 - 2020, academic peer reviewed journals which were written in the English language. This writer reviewed individual articles to ensure that the literature pertained to the transition and transfer from pediatric to adult care. Further primary source research papers referenced in the literature which continue to fundamentally inform current practice guidelines were also reviewed with the inclusion of a publication as far back as the year 2002.

Twenty-nine pertinent publications are presented in this review. The literature focuses on optimal timing of transition and transfer for adolescent and young adult patients (age 18-21 years), barriers to successful transition, assessment of transition readiness, transition resources and the role of the PCP. Items that were excluded included duplicate articles, thesis papers, editorials, and those which did not pertain to the transition from pediatric to adult care.

Several themes emerged in the literature are discussed below which highlight the importance of patient-centered, developmentally appropriate, coordinated transition and transfer of care from pediatric to adult health care setting for young adults with and without SHCN.

### **Barriers to Transfer**

The transfer of care can be an overwhelming process to patients, their families, and health care providers. Pediatric health care is typically family-centered, whereas the adult care model is more patient focused. Pediatricians are accustomed to leading discussions with parents, whereas adult providers primarily communicate directly with the patient. Adolescents want to be participants in their care and have expressed the importance of being introduced to the adult setting before transfer (Burstoum et al., 2016). During the transition, patients require education about their overall health and any complex conditions so they may gradually assume responsibility for their health care.

The most significant obstacle is a lack of communication and an informal approach to transition planning. This results in adolescents and young adults feeling anxious and unprepared for the transfer to adult care. In a study by Jensen et al., (2017) in a cohort of patients aged 16-to-25-years, fewer than half of the individuals reported ever having discussed transition to adult provider with their current subspecialty provider. Additionally, almost half (46%) either never or rarely saw the pediatric provider independently for part of the visit, although guidelines from the AAP, AAFP and ACP 2011 recommend that adolescents begin seeing providers independently for at least part of the visit at age 14.

Patients have reported difficulty adjusting to an autonomous adult healthcare environment from the more paternalistic setting of pediatric care (Freed & Hudson, 2006; Mackie et al., 2009) and often site a lack of confidence in their adult providers. Patients and families who develop long-standing trusting relationships with the pediatric clinicians who have been involved in their care may be reluctant to transfer care (Willis, 2020). These differences in healthcare settings present challenges for parents and caregivers of children with special health care needs particularly if they have not been effectively prepared for this change. Accessing appropriate medical services is complicated for adolescents and with SHCN due to challenges which prevent the transfer of medical records (Gleeson & Turner, 2012), patient health care literacy, developmental delays and lapses in insurance coverage (Reid et al., 2004; Gurvitz et al., 2013). Continuation of health insurance coverage has been an ongoing issue in health care transitions, although some improvement has occurred in the last decade. The Affordable Care Act and Medicaid expansion were both influential in ensuring better access to care and reducing gaps in coverage (Willis, 2020)

## **Lapse of Care and Patient Outcomes**

Lapses in medical care is common among young adults and has led to significant health consequences. In this situation, health outcomes after transfer demonstrate higher risks of morbidity and mortality for young adults (Blinder et al., 2015; Greutmann et al., 2015; Lebrun-Harris et al., 2018). According to Yeung et al. (2008), adult congenital heart disease patients who had lapses in care were 3.1 times more likely to need an urgent cardiac intervention. Patient reported reasons for lapse of care included not being told that cardiac follow up was required, non-compliance with recommendations due to feeling well, living in a location far away from qualified specialty providers, and fear of negative experiences in adult oriented care (Yeung et al., 2008, Gurvitz et al., 2013).

As previously mentioned, many young adult patients have misconceptions regarding the need for preventative care and lifelong surveillance resulting in potentially preventable adverse outcomes. Patients with lapses in care have been found to have an increased risk of hospital admissions, need for urgent intervention, and an increased chance of a new diagnosis being made at time of re-presentation (Gurvitz et al., 2013). If providers do not clearly convey the need for uninterrupted care, there is a chance the patient may seek medical care at a later time during a crisis situation.

One multi-site study in America included 922 participants ( $\geq 18$  years of age) with congenital heart disease demonstrated that 42% of subjects experienced gaps in cardiac care greater than three years (Gurvitz et al., 2013). The first lapse in care commonly occurred around 19 years, a time when young adults are attending college and the transition to adult services is contemplated (Gurvitz et al., 2013). The most common reasons for gaps included feeling well, unaware follow-up was required, and complete absence from medical care. The presence and

timing of this gap in care are consistent with those cited in other literature concerning health care transition, which similarly demonstrates that patients are often lost to follow-up or more likely to require urgent interventions or have undertreated medical conditions (American College of Cardiology; 2016; Gurvitz et al., 2013).

### **Timing of transfer**

The actual timing of transfer should be determined by a consensus of pediatric and adult providers, the patient, and their family. If possible, the transfer of care should occur electively at a time of medical stability, as opposed to during pregnancy or clinical decompensation. This allows for the adult practitioners to develop a relationship with the patient in a controlled environment, as opposed to during a time of chaos for the patient and their family (Cotts, 2018).

As young adults make the shift from a family-centered pediatric model of care to an autonomous adult model, self-management and self-advocacy skills become essential. College is a critical time for patients to transition since this developmental stage is characterized by a series of physical, cognitive, social, and emotional changes that must be balanced along with the management of their chronic disease (Acuña Mora et al., 2019).

It is essential that young adults with SHCN become familiar with their medications, side effects disease consequences, and future potential complications as they gain increased autonomy to transition through adolescence into adulthood. Sudden and unexpected transfers of care have resulted in significant issues in young adults with chronic illness such as being lost to follow-up or forgoing care, poor adherence to medical treatments, failure to establish a connection with an adult provider and increased hospitalizations (Willis, 2020). The transfer process is not complete until the young adult develops a relationship with adult providers and feels empowered to take responsibility for their own health care decisions (Habibi et al., 2017).

## **Identification of Patients Ready for Transition and Transfer**

Transition readiness requires advance planning and preparation. Preparation and planning are essential to ensure a smooth transfer and a positive experience for all involved, including providers and clinicians. Adolescents with chronic conditions must be knowledgeable about their condition and involved in decisions that impact their care. Although patients and families tend to rely on guidance from their providers, many young adults report they have not received healthcare transition counseling (Dwyer-Matzky et al., 2017; Sawicki et al., 2011). Routine assessment of transition readiness is recommended to facilitate recognition of deficits and interventions to promote successful transition outcomes (Uzark et al., 2015). The lack of validated tools for providers may inhibit such assessments and patient counseling.

In a 2002 joint consensus statement, the AAP/AAFP/ACP recommended providers regularly assess transition readiness skills using an objective measure. The Transition Readiness Assessment Questionnaire (TRAQ), developed by Sawicki and colleagues, is a non-disease-specific self-report measure which has been well-validated across multiple disease processes (Sawicki et al., 2011; Wood et al., 2014). The 29-question assessment tool intended to be filled out by the youth patient (age 12-17) and utilized by the pediatric care team to begin the conversations about the skills needed to transition to adult-oriented healthcare. The tool measures patients' transition readiness in five different domains: managing medications, appointment keeping, tracking health issues, talking with providers, and managing daily activities. These domains represent the skills essential for self-management and health care utilization for chronic medical conditions. Greater transition knowledge and perceived self-efficacy are associated with better psychosocial quality of life (American College of Cardiology, 2016).

### **Role of Primary Care Providers (PCPs)**

Ensuring adequate care during the transition period requires close coordination between the patient's PCP and various specialists. As defined by their medical home policy statement, the AAP recommends that all individuals with chronic lifelong healthcare needs should have access to a "medical home" (American Academy of Pediatrics 2011; Sabel et al., 2011). The role of the PCP in this setting is exceedingly important. Having a medical home has been associated with an increased probability that children with special health care needs receive adequate transition planning.

According to the 2011 AAP policy statement, the PCP must provide patient and family-centered care. The PCP should be aware of the patient's baseline functional status and should identify signs or symptoms potentially related to chronic conditions and what might represent worsening of the patient's condition. To achieve this, PCPs should maintain easily accessible, centralized, and comprehensive "passport" of the patient's entire medical history. These records should include the patient's diagnosis, surgical history, and current medications (AAP, 2011).

### **Formal Health Care Transition Planning**

The use of structured pediatric-to-adult HCT programs is currently recommended to optimize patient and health-system outcomes. Given the importance of medication-related knowledge and healthcare system navigation skills to successful care transitions, there are opportunities for PCPs to develop practice specific HCT policies and programs. As part of the transition process, patients gain the responsibilities of healthcare logistics, including accessing medical information, prescription fills and refills, clinic appointments, and maintaining insurance coverage. Preparing patients for these responsibilities, as with other components of patient and caregiver education, should be done over a period of time through ongoing education during well

visits (Gupta, 2014). The amount of information and skills required to successfully navigate the adult healthcare system can be overwhelming. Thus, providing some education at each encounter for education is recommended, as that approach can help improve understanding, engagement, and retention. Over time, the patient should develop problem-solving and decision-making skills in partnership with their healthcare team.

Saidi and Kovacs (2009) proposed a stepwise process for developing a transition program, described as a “transition to transfer.” The practitioner begins by increasing personal knowledge related to the transition process by reading relevant guidelines and existing data. Parents and legal guardians should be engaged early in the transition process to ensure the pursuit of common goals. The practitioner further facilitates the process by educating colleagues, obtaining external consultation and support from specialists (Saidi & Kovacs, 2009). Adolescents who have a strong relationship with their PCP are more likely to have a successful transition to adult care and receive appropriate health maintenance advice through continuous care (LeCompte et al., 2016). The PCP can play an active role in transitioning young adults from the pediatric to adult care setting in a seamless manner as opposed to an abrupt transfer (Gupta, 2014).

### **Transition Resources**

The end of the pediatric period is burdened with uncertainties and risks, especially for children with chronic illnesses and disabilities. Despite having position statements from professional organizations and several proposed models, barriers to effective transition care persist and widespread implementation of a standardized approach to HCT has yet to be adopted.

Mahan et al. (2017) proposed that HCT can be divided into three phrases: (1) setting the stage, initiation of HCT services and readiness assessment; (2) moving forward, ongoing

provision of HCT services; and (3) reaching the goal, transfer of care and transition to adulthood. To incorporate HCT interventions into healthcare systems, Mahan et al. (2017), recommended a quality improvement approach such as those offered by the Center for Health Care Transition Improvement Model (Six Core Elements). Developed in 2009, The Six Core Elements of Health Care Transition has been promoted by Got Transition, a cooperative agreement between the Maternal and Child Health Bureau and the National Alliance to Advance Adolescent Health. This approach provides a framework for assessing progress towards improving transition processes. The model (Appendix A) includes recommendations in regard to practice specific transition policies, patient tracking and monitoring, transition readiness assessments, transition planning, transition of care and transfer completion (Got Transition, n.d.).

The American College of Physicians (ACP) has also developed disease-specific tools that consist of information adapted from the Got Transition Six Core Elements of HCT which have been customized to assist with and improve the transition experience for young adults with specific diseases and/or chronic conditions. The tools include the following disease-specific tools: transition readiness assessments, medical summary/transfer record and self-care assessments. Disease specific tools are available for the following subspecialties: general internal medicine (intellectual/developmental disabilities and physical disabilities), cardiology, endocrinology, gastroenterology, hematology, nephrology, and rheumatology.

The most logical solution to address the gaps in clinical practice is for PCPs to increase awareness of transition and transfer, provide patient and family education and collaborate with adult providers and specialists. In depth conversations with patients should address how to navigate the healthcare system and cover topics such as disease specific risk factors to avoid,

medication names, doses, possible side effects or interactions with other drugs, as well as future family and career planning (Habibi et al., 2020).

### **Evidenced Based Practice: Implementation of an Educational Program**

Qualitative research has demonstrated that many young patients with SHCN do not possess sufficient knowledge about their condition (Burstrom et al., 2016). Primary care considerations include educating patients about their diagnosis, providing surveillance and screening, addressing sexual and reproductive health and assessing for high-risk behaviors. These issues must be addressed systematically and comprehensively to ensure that adolescents and young adults are prepared to assume complete responsibility for their health.

The goal of a formal HCT program should be to prepare young adults for the transfer of care through the provision of continuous treatment that is patient centered, age and developmentally appropriate, flexible and comprehensive (AAP, 2011). Further education of PCPs will provide resources to empower patients to engage in communication, decision making, independent self-care, and informed decision making in order to enhance their quality of life. With a framework for HCT coupled with additional resources, PCPs can strategize the development of interventions such as a reminder for follow-up appointments and discussions about the medications and side effects to improve the skills of adolescents with chronic conditions with baseline TRAQ scores (Chan et al, 2019).

### **Theoretical Framework**

The Theory of Goal Attainment 1968/2007 by Imogene King was used to guide this project. This middle range theory is described as a dynamic, interpersonal relationship in which a patient grows and develops to attain certain life goals. The process of goal attainment occurs

when a client in need of a provider's services enters a reciprocal relationship with a provider where both parties are mutually present for a purposeful interaction. (King, 2007).

The framework (Appendix B) consists of three interacting systems: personal (individual), interpersonal (patient-provider), and social (health care system) (King, 2007). Each of these systems has its own set of concepts. The concepts for the personal system are perception, self, growth and development, body image, space, and time. The concepts for the interpersonal system are interaction, communication, transaction, role, and stress. The concepts for the social system are organization, authority, power, status, and decision-making (King, 2007).

King's (1992) theory was modified and used to reframe the process of HCT as a shared goal between patients with SHCN and multidisciplinary providers as follows: (1) health is attained through appropriate patient-provider relationship; (2) patient and provider must have a mutual understanding of one another; (3) the goals and functions of patient and provider need to be in line with each other; and (4) the provider must use all his/her knowledge to establish relationship and set goals. These four elements will facilitate the attainment of patients' goals. The Theory of Goal Attainment defines nursing as "a process of action, reaction and interaction by which nurse and client share information about their perception in a nursing situation" and "a process of human interactions between nurse and client whereby each perceives the other and the situation, and through communication, they set goals, explore means, and agree on means to achieve goals" (King, 1992 p. 20).

One focus of the dynamic interpersonal system (Appendix C) is the provider-client relationship and mutual goal setting. Communication is the process of communicating information and turning information from one state to another while transaction is a meaningful interaction between people and environment to attain the goal of health. The process of goal

attainment occurs when a client in need of a provider's services enters a reciprocal interpersonal relationship with a provider where both parties are mutually present for a purposeful interaction (King, 2007). During the process of transition, the patient and provider will communicate information in order to mutually set goals (interaction) and then act to empower attainment of those goals (transaction) and ultimately improve patients' quality of life (King, 2007).

## **Methods**

### **Goals, Objectives and Expected Outcomes**

The goal of this DNP project was to increase PCP confidence in engaging conversations about transition and encourage them to begin doing so at age 12 to 14 years as recommended by the AAP. The overall objective was for the provider toolkit to be valued as a practical resource to facilitate successful transition from pediatric to adult care. The goals, objectives and expected outcomes are presented in Table 1.

Table 1. *Goals, Objectives & Expected Outcomes*

Goals	Objectives	Expected Outcomes
1. Evaluate PCPs confidence in engaging in conversations about transition with patients and their families.	Determine PCP confidence in engaging in conversations about transition with patients and their families. Establish age at which providers begin conversations about transition.	PCPs will report feeling somewhat to moderately confident engaging in conversations beginning primarily around age 18 or later prior to an educational intervention.
2. Assess provider interest in utilizing a validated tool for measuring transition readiness and a provider toolkit to streamline the transition process.	Determine if providers are currently using any validated tools to assess transition readiness.	PCPs will convey interest in a provider toolkit.

3. Provide information and validated tools to PCPs to be used in clinical practice to increase confidence in engaging in transition practices. Information will be presented via an educational intervention.	Increase PCP confidence, knowledge and interest in facilitating successful transition from pediatric to adult care.	PCPs will report increased confidence and confirm they learned new concepts about HCT. PCPs will pilot the TRAQ at their practice.
4. Evaluate the impact of this intervention on PCPs in improving transition from pediatric to adult care	Assess effectiveness of educational intervention.	PCPs will report increased confidence in providing transition service and express an intention to begin conversations at an earlier age as recommended by the AAP. PCPs will view the toolkit as a valuable resource to be employed in future practice.

## **Project Design**

The DNP project initially began with video conference meetings with the DNP student's mentor, Director of the organization's Adult Congenital Heart Disease Clinic and later with the Director of Pediatrics at the project site. Verbal agreement of the project proposal was obtained from previously mentioned stakeholders, followed by a formal letter of support. The costs associated with this project included only the participants' time.

An integrative literature review was performed to investigate the goals and challenges of transition and transfer as well as to identify potential solutions to address the gap in clinical practice. Based on the findings, the DNP student created a provider toolkit to facilitate future patient transitions of care. The QI project included an informational presentation of the toolkit with the distribution of pre and post intervention surveys for all participants.

## **Project Site and Population**

The project site was a community primary care practice which is affiliated with a larger healthcare organization. The site is located in Revere, Massachusetts. According to U.S. census data, Revere has a population of 53,864 people with a median household income of \$54,182. The largest ethnic groups in Revere are White (62.41%), Hispanic or Latino (24.38%), Black or African American (4.32%), Asian or Pacific Islander (5.53%) and other (1.65%).

The pediatric practice provides children of all ages with personalized primary care, preventive and health maintenance care, as well as specialty pediatric services. The providers encourage regular well child visits for healthy children. They also coordinate care for children with disabilities, chronic illness and other complex medical conditions such as asthma, obesity, anxiety/depression, cystic fibrosis, and congenital heart diseases. The primary languages spoken by patients at this clinic include English, Spanish, and Portuguese.

Prior to implementation of this project, the practice did not have a formal transition policy and providers varied on their approaches to preparing patients for transition and the age at which they transferred patients to adult providers. Prior to the educational intervention the practice had not adopted a standardized readiness assessment tool for use with transition aged youth. PCPs varied in their process of identifying transition-aged youth but most waited until close to the age of transfer to engage in discussions about transition.

## **Ethical Considerations/Protection of Human Subjects**

Participation in this QI project was voluntary, and participants could choose to drop out at any time. The project did not require any interaction with patients, patient families or the review of patient records. It was determined by the organization that this project did not meet the criteria for research and was deemed a QI project. Internal Review Board (IRB) approval from

The University of Massachusetts, Amherst (UMass) was requested prior to initiating the DNP Project. The proposed project did not meet the definition of human subject research under federal regulations [45 CFR 46.102(d)]. The UMass IRB letter of exemption can be found in Appendix F. Without any identified risks to participants, this DNP project offered great potential for benefits to providers and patients.

### **Toolkit Creation**

The provider toolkit (Appendix H) was developed with the objective of providing PCPs with a framework to implement the “Six Core Elements of Health Care Transition,” modeled after the American Academy of Pediatrics, American Academy of Family Physicians, and American College of Physicians 2011 clinical report on supporting transition. Included in the toolkit was an overview of Got Transition’s Six Core Elements, an adapted version of the Transition Readiness Assessment Questionnaire (TRAQ), and additional patient/provider resources. Patient resources included the Got Transition’s Family Toolkit: Pediatric-To-Adult Health Care Transition. This guide includes information about what to expect during HCT and a tentative timeline which provides details about what to expect and questions to ask during the process beginning at age 12 until the age of 25.

Additional patient resources included links to smartphone applications for adolescents to set up their medical ID and/or health passport and track their medications as well as information on health insurance coverage options and requirements. Provider resources included condition specific transition readiness tools from the American College of Physicians for patients with intellectual/developmental disabilities and physical disabilities as well as other subspecialties. To address concerns regarding reimbursement for transition services, a coding and reimbursement

tip sheet developed by Got Transition and the American Academy of Pediatrics was also incorporated.

### **Project Implementation**

In January 2021, informational emails were sent from the DNP student to pediatric providers at the health care center. The email included a brief student introduction, a statement about the purpose of the project and an invitation to participate in an optional educational intervention with the presentation of a provider toolkit. The aim of the educational intervention was to educate PCPs about the current gap in clinical practice and the benefits of a structured approach to guide patients through their transition of care from the pediatric to adult care setting.

A PowerPoint presentation, developed by the DNP student provided an overview of the current evidence-based research and guidelines as well as an overview of the provider toolkit elements to be implemented in clinical practice. Due to the current circumstances surrounding the COVID-19 pandemic, an in person educational session was deemed to pose a greater risk than benefit. Instead, a one-hour Zoom presentation was offered as an alternative. The provider toolkit and presentation were distributed electronically to attendees a week prior the intervention. The educational session offered by the DNP student took place on March 1, 2020 from 12 p.m. until 1 p.m. Attendees included 8 pediatric primary care providers. The complete project timeline can be found in Appendix G.

### **Data Collection**

The DNP student used qualitative methods for data collection and analysis which resulted in successful completion of set goals and objectives. Provider confidence in engaging in conversations about transition as well as their interest in piloting the use of a validated tool to assess transition readiness and a provider toolkit were measured with pre and post intervention

surveys. Participants' responses were collected via Survey Monkey software and maintained confidentially. In order to ensure anonymity, participants responses on the post-intervention surveys were not matched with their pre-intervention surveys.

### **Measurement Instruments**

Prior to the educational presentation, participants were sent a link to the pre-intervention questionnaire via email. Immediately following the educational intervention, attendees were sent a follow-up email thanking them for their time and participation with a link to the post intervention questionnaire. Qualitative surveys which included Likert scale, open ended and dichotomous yes/no questions were created and distributed electronically by the DNP student. Recipients were informed that their feedback on both surveys was confidential and would remain anonymous.

The 7-item pre intervention questionnaire (Appendix D) consisted of seven questions including: 1) As a pediatric provider, how would you rate the importance of preparing your patients for the transition to the adult care setting? 2) How confident do you feel about engaging in conversations with your patients and/or their parents about the transition of care to the adult setting? 3) At what age do you typically begin to discuss transition planning with your patients? 4) At what age do you typically transfer a patient to an adult provider? 5) What are some of the barriers which prevent you from engaging young adult patients in their care? 6) Are you currently using any validated tools to assess for transition readiness? 7) Would you be interested in utilizing an evidenced based toolkit in your practice to coordinate transition planning and transfer of care for young adults?

The pre-intervention survey inquired about the barriers which prevent providers from engaging young adults in their care. The providers' responses (Table 2) were collected and

placed in an excel spreadsheet for analysis. Information provided was utilized to develop and deliver practice-based solutions to be included in the provider toolkit.

Table 2.

*Provider Perceived Barriers to Transition*

Pre-Intervention Survey Question 5	Responses <i>n</i> = 7 (one provider skipped this question)
What are some of the barriers which prevent you from engaging young adults in their care?	<ul style="list-style-type: none"> <li>• Time constraints</li> <li>• Too many other important things to do during the visit</li> <li>• Not returning my calls, mental health issues, no shows, moving to college</li> <li>• Lack of regular follow up after going to college (missed appointments)</li> <li>• Sometimes distance from school seems so minimize concerns thus harder to motivate patient for continued efforts</li> <li>• Parents who continue to accompany their children even after they turn 18</li> <li>• Patient fear of leaving a provider who has known them their whole lives especially if they have complex medical problems</li> </ul>

The DNP student expected that after the presentation of the provider toolkit PCPs would be more confident in engaging in conversations about transition and transfer, intend to initiate transition planning at prior to age 16 and provide positive feedback in regard to implementing the tangible toolkit in their practice to enhance care coordination. The 9-item post- intervention questionnaire (Appendix E) included the following questions: (1) After the presentation, how would you now rate the importance of preparing your patients for transition to the adult care setting? (2) After the presentation, how confident do you now feel about engaging in conversations with your patients and/or their parents about transition planning and the eventual

transfer of care to an adult provider? (3) Do you anticipate that you will start spending alone time with your patients at an earlier age during preventative care visits? (4) At what age do you now plan to begin to discuss transition planning with your patients? (5) Do you plan to use the TRAQ form in the future to assess for transition readiness? (6) Do you plan to utilize the Provider Toolkit in your practice to coordinate health care transition for your young adult patients? (7) Did you learn any new concepts about health care transition as a result of this presentation? (8) The toolkit provides me with actionable behaviors to improve transition of care. I will access/refer to the toolkit in the future. (9) I would recommend the toolkit to my colleagues (10) Are there any additional items that would be beneficial to include in the Provider toolkit?

### **Data Analysis**

Following the presentation, the DNP student compared pre/post provider confidence in engaging in conversations with patients and/or their parents about transition planning as well as pre/post age at which providers begin to discuss transition planning with their patients. To determine if there was a significant difference between pre and post intervention values, survey results were statistically analyzed using IBM SPSS Statistics. One-sample t tests were used to account for the small sample size ( $N=8$ ) and the fact that the participants' responses on the post intervention survey were not matched with their responses on the pre-intervention survey. SPSS Statistics uses a statistical significance at the  $p < .05$  level.

### **Results**

Statistical analysis revealed that changes in provider confidence in engaging in conversations with patients and/or their parents about transition planning (Table 3) was not statistically significant ( $p = 0.195$ ), meaning the DNP student could not conclude a significant difference existed between mean survey scores on the pre/post intervention surveys. However,

calculation of Cohen's  $d$  revealed an estimated effect size of 0.641, indicating a moderate impact of the educational intervention.

The age at which providers to begin to discuss transition planning with their patients (Table 4) was statistically significant ( $p = 0.020$ ), therefore it can be concluded that a significant difference exists between mean scores on the pre/post intervention surveys. Two providers planned to start discussing transition planning at the age of 12 to 14 years as recommended by the AAP, AAFP and ACP. Prior to the educational intervention, providers disclosed they felt this was too early to commence transition discussions. Pre-intervention surveys revealed that prior to the educational session, several providers ( $n = 3$ ) delayed transition discussions until at least age 17-18 with some providers ( $n = 3$ ) waiting until the patient was between the age of 19 - 20.

No changes were noted in pre/post rank of importance of preparing patients for transition to the adult health care setting. In both the pre-intervention survey and the post intervention survey providers rated the importance of preparing patient for the transition as either moderately important ( $n = 4$ ) or extremely important ( $n=4$ ).

After the intervention, 62.5% ( $n = 5$ ) of providers expressed an interest in increasing alone time with patients during preventative care visits as recommended by the AAP. Alone time with patient was not measured in the pre-intervention survey.

Prior to the intervention, 100% ( $n = 8$ ) of providers responded that they were not using a validated tool to assess for transition readiness. 100% ( $n = 8$ ) of providers expressed an interest in utilizing an evidence-based toolkit to coordinate HCT. Cross tab statistical analysis using the McNemar test revealed a significant ( $p = .031$ ) difference in interest in using a standardized tool to assess transition readiness.

After the intervention, 75% of providers ( $n = 6$ ) responded that they learned new concepts about HCT, would recommend the toolkit to their colleagues, and plan to refer to the toolkit and utilize the TRAQ in future practice. One provider offered the suggestion to translate elements of the provider toolkit into multiple languages such as Spanish, Portuguese and Arabic.

Table 3.

Confidence in engaging in conversations about Transition Planning and Transfer of Care

Confidence Level	Pre- Intervention (N = 8)		Post- Intervention (N = 8)		Significance based on one-sample t test p-value
	N	%	N	%	
Not at all confident	0	0.00%	0	0.00%	0.195
Somewhat confident	2	25.00%	1	12.50%	
Moderately confident	6	75.00%	5	62.50%	
Extremely confident	0	0.00%%	2	25.0%	

Table 4.

Age at which providers begin to discuss Transition Planning and Transfer of Care

Age Group	Pre- Intervention (N = 8)		Post- Intervention (N = 8)		Significance Based on one- sample t test p-value
	N	%	N	%	
12-14	0	0.00%	2	25.00%	0.020
15- 16	1	12.50%	2	25.0.0%	
17 -18	3	37.50%	3	37.50%	
19-20	3	37.50%	1	12.50%	
No formal preparation	1	12.50%	0	0.00%	

## Discussion

While the significance of structured transitional care for adolescent and young adults has been increasingly identified in the literature over the past several decades, current evidence has highlighted opportunities to develop coordinated transition processes for patients aged 18 to 21 years. Multiple patient/provider and organizational challenges impede the successful transition of healthcare services for young adult patients. Standardized transition policies and protocols in the primary care setting may help to overcome some of the barriers and ultimately improve the HCT process for this patient population.

There is an increasing demand for evidence informed transition programs for the adolescent and young adult population driving the force for institutional recognition and support for structured health care transition programs, as well as policy changes to support development, implementation, and evaluation of such programs. Leadership, multidisciplinary providers, and administrative coordinators at the clinic were supportive and open to discussion and participation with the DNP student. Facilitators of this project included motivated primary care providers and adult specialists. The Director of Pediatrics at the project site, was eager to assist with this initiative and was receptive to the opportunity for an educational intervention.

The participants demonstrated an interest in learning, were engaged with the material, asked several questions during the presentation and took advantage of opportunities to share their professional experiences. Providers expressed concern about the added time/burden of adding on an additional questionnaire for patient.

The project results are consistent with the claim that teamwork is essential to improving coordination and communication in the HCT process (White et al., 2018). As a result of this project, there was increased provider collaboration with social work in order to share the

workload in piloting the TRAQ. Providers recognized that social work's professional understanding of family dynamics and cultural implications provide the opportunity for unique collaboration with the health care team, family, and community resources to facilitate successful transition.

There are at least three potential limitations concerning the results of this project. First, the project was conducted at a single pediatric primary care practice. In order to ensure social distancing due to the pandemic, a one-time educational session was provided via Zoom rather than in person which could be considered a limiting factor for participant involvement and data collection. Surveys were collected electronically from a small sample of pediatric PCPs. Despite these limitations, the present project enhanced the understanding of the barriers and challenges patients and providers must overcome in order to effectively prepare adolescent and young adults for their eventual transfer to the adult health care setting.

Providing tangible toolkits and adaptable tools to facilitate transition and transfer screening in medicine-pediatric primary care is the first step in a larger process of providing developmentally appropriate, patient-centered uninterrupted care. PCPs are in an ideal position to educate and empower adolescent patients to engage patients in their health care. King's theory of goal attainment can be applied to the transiting planning process when the primary care team implements elements of provider tool kit for mutual goal setting. Identification of patients who meet the requirements for transition readiness will provide the starting point for facilitating the successful transition of adolescent and young adult patients driven by the providers who know them best—their primary care team. The TRAQ will be piloted at this practice to facilitate communication with the goal of maximizing the patient's quality of life and promoting positive health outcomes.

Future evidence-based interventions and educational offerings will provide the opportunity PCPs with innovative strategies to empower adolescents and young adults with and without SHCN to manage their own health and effectively establish a connection with adult providers and specialists when appropriate.

### **Conclusion**

In conclusion, the provider toolkit and educational intervention were well received by participants. The project outcomes revealed the potential success of applying an organized approach to transition from pediatric to adult health systems through the application of Got Transition's Six Core Elements of Health Care Transition and implementation of the TRAQ at the project site. Future studies should examine the employment of a structured HCT processes on a larger scale and measure the impact of interventions on patient outcomes.

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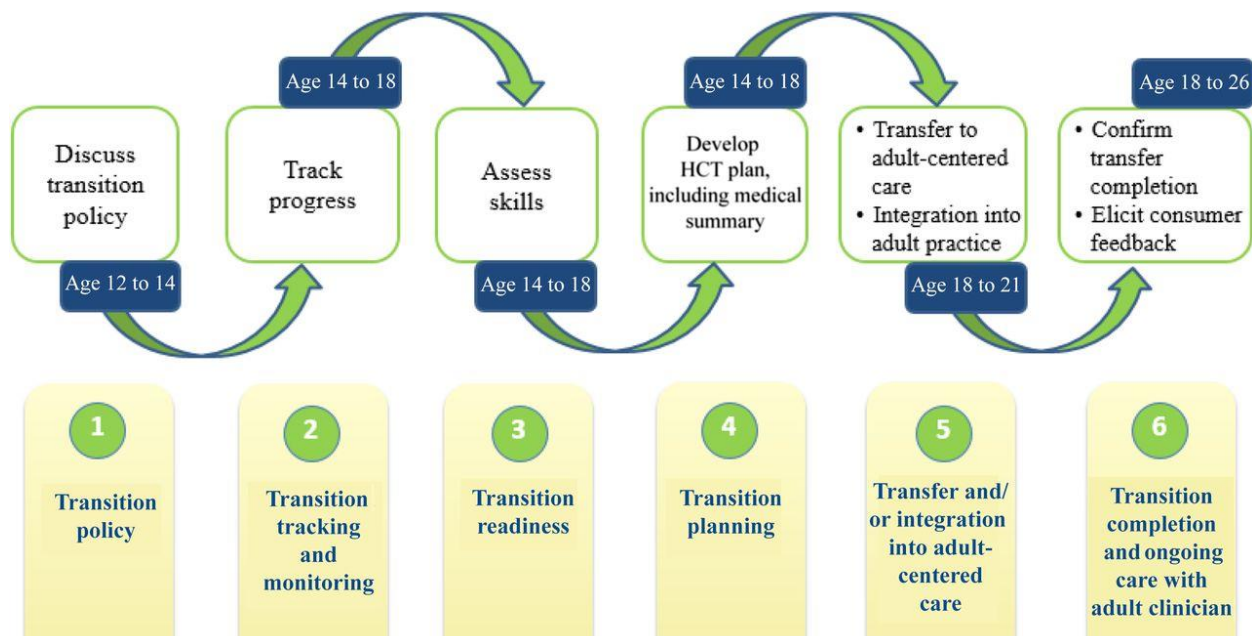
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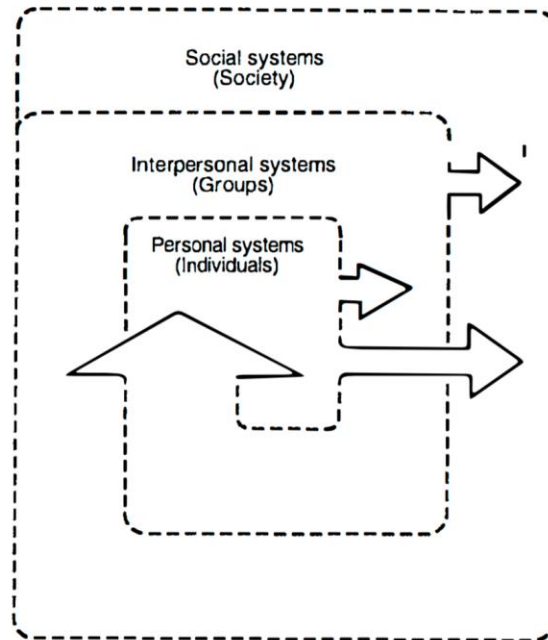
## Appendix A

### Got Transition Six Core Elements



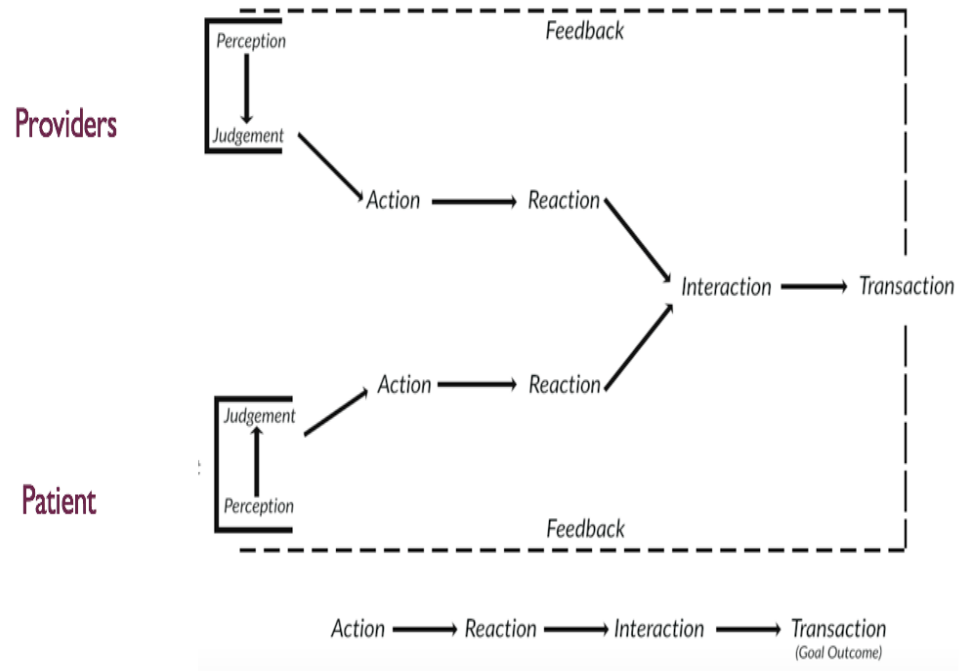
## Appendix B

### King's Theory of Goal Attainment (King, 2007)



## Appendix C

King's Theory of Goal Attainment – Interpersonal System (King, 2007)



**Appendix D**  
**Pre-Intervention Survey**

1. As a pediatric provider, how would you rate the importance of preparing your patient for transition to adult setting?

1	2	3	4
Not Important	Somewhat Important	Moderately Important	Extremely Important

2. At what age are you typically transferring your patients to an adult provider?

18	19-20	21-22	>22
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3. At what age do you begin preparing your patients for transition?

12 -14	15-16	17-18	19-20	No preparation
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4. How confident do you feel about engaging in conversations with your patients and/or their parents about the transition of care to the adult setting?

1	2	3	4
Not Confident	Somewhat Confident	Moderately Confident	Extremely Confident

5. What are the barriers which prevent you from engaging young adult patients in their care?

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6. Are you currently using any validated tools to assess for transition readiness?

Yes	No
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7. Would you be interested in utilizing an evidence-based toolkit in your practice to coordinate care of young adults?

Yes	No
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## Appendix E Post Intervention Survey

1. After the presentation, how would you now rate the importance of preparing your patients for transition to the adult care setting?

1	2	3	4
Not Important	Somewhat Important	Moderately Important	Extremely Important

2. After the presentation, how confident do you now feel about engaging in conversations with your patients and/or their parents about transition planning and the eventual transfer of care to an adult provider?

1	2	3	4
Not at all confident	Somewhat Confident	Moderately Confident	Extremely Confident

3. Do you anticipate that you will start spending alone time with your patients at an earlier age during preventative care visits?

Yes                      No

4. At what age do you now plan to begin to discuss transition planning with your patients?

12 -14                      15-16                      17-18                      19-20                      No preparation

5. Do you plan to use the TRAQ form in the future to assess for transition readiness?

Yes                      No

6. Do you plan to utilize the Provider Toolkit in your practice to coordinate health care transition for your young adult patients?

Yes                      No

7. Did you learn any new concepts about health care transition as a result of this presentation?

Yes                      No

8. The toolkit provides me with actionable behaviors to improve transition of care. I will access/refer to the toolkit in the future.

Yes                      No

9. I would recommend the toolkit to my colleagues.

Yes                      No

10. Are there any additional items that would be beneficial to include in the Provider toolkit? If so, please share

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## Appendix F

### UMass IRB Exemption Letter

**UMassAmherst**

Human Research Protection Office

Mass Venture Center  
100 Venture Way, Suite 116  
Hadley, MA 01035  
Telephone: 413-545-3428

#### Memorandum – Not Human Subjects Research Determination

**Date:** February 12, 2021

**To:** Nicole Jones, College of Nursing

**Project Title:** *Supporting Transition of Care for Young Adults with Special Health Care Needs*

**HRPO Determination Number:** 21-49

The Human Research Protection Office (HRPO) has evaluated the above named project and has made the following determination based on the information provided to our office:

- The proposed project does not involve research that obtains information about living individuals [45 CFR 46.102(f)].
- The proposed project does not involve intervention or interaction with individuals OR does not use identifiable private information [45 CFR 46.102(f)(1), (2)].
- The proposed project does not meet the definition of human subject research under federal regulations [45 CFR 46.102(d)].

#### **Submission of an Application to UMass Amherst IRB is not required.**

Note: This determination applies only to the activities described in the submission. If there are changes to the activities described in this submission, please submit a new determination form to the HRPO prior to initiating any changes. **Researchers should NOT include contact information for the UMass Amherst IRB on any project materials.**

A project determined as “Not Human Subjects Research,” must still be conducted ethically. The UMass Amherst HRPO strongly expects project personnel to:

- treat participants with respect at all times
- ensure project participation is voluntary and confidentiality is maintained (when applicable)
- minimize any risks associated with participation in the project
- conduct the project in compliance with all applicable federal, state, and local regulations as well as UMass Amherst Policies and procedures which may include obtaining approval of your activities from other institutions or entities.

Please do not hesitate to call us at 413-545-3428 or email [humansubjects@ora.umass.edu](mailto:humansubjects@ora.umass.edu) if you have any questions.



Iris L. Jenkins, Assistant Director  
Human Research Protection Office

**Appendix G**  
**Project Timeline**

<b>Task</b>	<b>Sept 2020</b>	<b>October 2020</b>	<b>November 2020</b>	<b>December 2020</b>	<b>January 2021</b>	<b>February 2021</b>	<b>March 2021</b>	<b>April 2021</b>
Submit proposal to IRB for approval	X							
Complete integrative review		X	X					
Recruitment of local providers – Discussions with Stakeholders			X	X				
Create evidenced based resource packet for providers and staff.				X	X			
Create PowerPoint presentation for providers and staff.						X		
Present PowerPoint and distribute tool kit to providers							X	
Administer post-presentation evaluation survey.							X	
Analysis of outcomes							X	X

## Appendix H

### Primary Care Provider Toolkit for Supporting Transition of Youth from Pediatric to Adult Health Care

#### INTRODUCTION

For the purpose of this Toolkit, health care transition (HCT) is defined as the purposeful, planned movement of adolescents and young adults from child-centered to adult-oriented health care systems. HCT is a **process** where the responsibility for managing health care shifts from the parent/caregiver to the young adult. In an ideal setting, the patient should receive uninterrupted and developmentally appropriate medical care.

In 2018, The American Academy of Pediatrics (AAP), American Academy of Family Physicians (AAFP) and the American College of Physicians (ACP) updated their original 2011 clinical report on health care transition. This updated clinical report, “Supporting the Health Care Transition from Adolescence to Adulthood in the Medical Home,” provides practice-based quality improvement guidance on key elements of transition: planning, transfer, and integration into adult care.

Despite the recommendations, the 2016-2017 National Survey of Children’s Health revealed that the majority of youth (age 12-17 years old) with and without special health care needs (SHCN) are not receiving necessary support for transition from their health care providers. According to the data, less than 20% of youth receive appropriate transition support which suggests improvement efforts are necessary to promote lifelong positive health outcomes and well-being.

This toolkit was developed for primary care providers (PCPs) to utilize during HCT and includes resources for PCPs, patients and parents/caregivers. These tools can be used to facilitate successful pediatric to adult transition planning.




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White P.H. & Cooley W.C., Transitions Clinical Authoring Group, et al. (2018) Supporting the health care transition from adolescence to adulthood in the medical home. *Pediatrics*. 2018;142(5):e20182587.

Got Transition. State, Region, and National Health Care Transition Performance for Youth With and Without Special Health Care Needs: The National Survey of Children’s Health 2016-2017. Washington, DC: Got Transition, 2018

## BACKGROUND

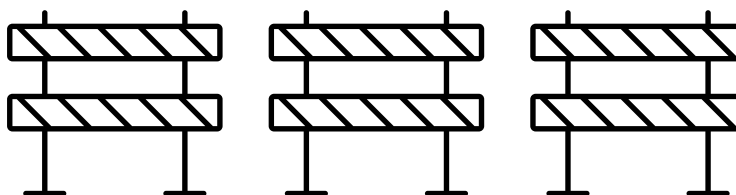
Adolescents and young adults are recognized as a vulnerable population in terms of higher rates of behavioral health risks and traditionally under-utilization of health care.

A smooth transition from pediatric/adolescent to adult healthcare is important for continuity of care, which has been associated with improved health outcomes, including lower frequency of hospital admissions and emergency room visits and increased use of preventive services.

The role of the pediatrician is to ensure an organized process to facilitate transition preparation, transfer of care, and integration into adult-centered health care. In an ideal transition scenario, the PCP will empower adolescents and young adults with and without SHCN to manage their own health care and effectively navigate health services.

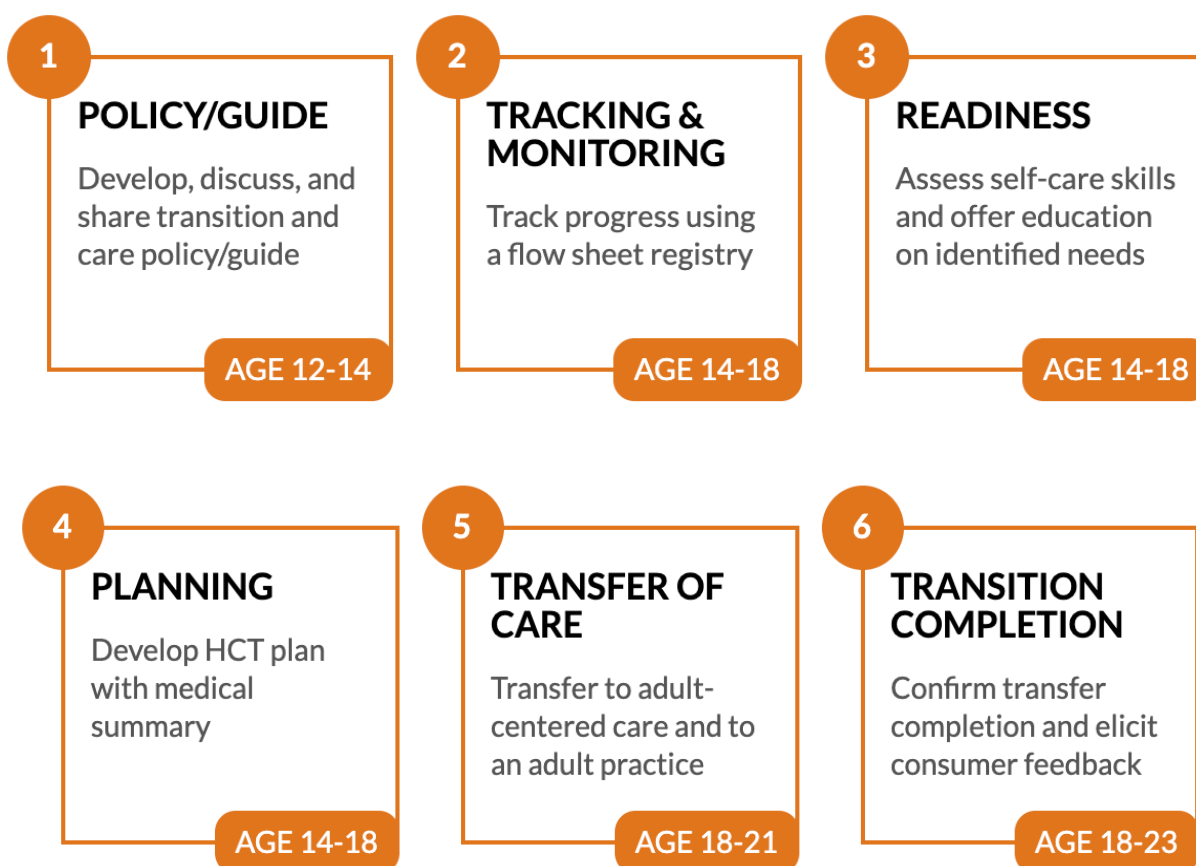
## BARRIERS TO SUCESSFUL TRANSITION

- Patients may fear leaving a provider who has known them all their lives, particularly if they have complex medical problems, developmental and/or intellectual disabilities, mental and/or behavioral health conditions.
- Parents who remain over involved (continue to schedule and accompany their children to their appointments) even after they turn 18
- Loss to follow up once patient enters college (misconceptions about health conditions or distance from provider)
- Time constraints during office visits



## GOT TRANSITION® SIX CORE ELEMENTS

Got Transition® is a program of the National Alliance to Advance Adolescent Health. The Six Core Elements define the basic components of a structured HCT process, which include establishing a transition and care policy/guide, tracking and monitoring progress, administering transition readiness assessments, planning for an adult approach to care, transitioning to an adult approach to care, and continuing with ongoing care. This HCT approach, recommended in the 2018 AAP/AAFP/ACP Clinical Report, can be customized for practices serving young adults.



Overview: Transitioning Youth to an Adult Health Care Clinician  
<https://www.gottransition.org/6ce/?leaving-overview>

## 1. TRANSITION POLICY

Below is a transition policy which was created by the MGH Transitions Committee and Transitions Program. It is recommended that this policy be distributed to adolescents and their parents beginning at age 12 to 14 and regularly during wellness exams in accordance with AAP/AAFP/ACP recommendations.



# Transition of Care Policy for Youth and Young Adults

Massachusetts General Hospital is committed to a transition from pediatric care to adult care. We feel that a smooth transition from adolescence to young adulthood requires preparation and planning. We look forward to working with you and your family on this journey.

### MGH TRANSITION POLICY

"As recommended by the American Academy of Pediatrics, we at Massachusetts General Hospital want to support your smooth transition from our practice to adult-oriented care. Our office endorses and follows the policies below to help you (and your parents) prepare you for adult care and adulthood.

- Transition planning, preparation, and training will start by age 12.
- At age 18, most youth in our practice will transition to an adult model of care with modifications as needed for youth with intellectual disabilities.
- We respect the preferences of the youth and family regarding the eventual transfer of care to an adult primary care medical home, but this tends to occur between age 18 and 22.
- A health summary which includes past medical history, current medications and pertinent care plan with specific recommendations will be provided prior to transfer."

[Click here for a PDF copy for your practice.](#)

## 2. TRACKING & MONITORING (AGES 14-22)

A transition registry can be used to identify track and monitor youth throughout the pediatric-to-adult health care transition process. Goal is to stratify those that need more HCT support (non-compliance in pediatric setting, low SES, cognitive challenges)

A transition registry can be completed on paper, in an Excel spreadsheet, or if possible integrated into the EMR.

Sample Transition Registry from Got Transition’s “Transitioning Youth to an Adult Health Care Clinician” <https://gottransition.org/6ce/?leaving-registry>

Sample transition flow sheet from Got Transition’s “Transitioning Youth to an Adult Health Care Clinician” <https://gottransition.org/6ce/?leaving-flow-sheet>

## 3. TRANSITION READINESS ASSESSMENT (BEGIN AT AGE 14–16)

Providers should begin to allocate time alone with patient (Adult Model of Care). Regular transition readiness assessment should be conducted to identify and discuss with youth and parent/caregiver their needs for self-care and how to engage in health care services. Continue assessments throughout the HCT period until the youth has transferred.

Adolescents and young adults should be able to identify their medical problems, medications and allergies without support from their parents, or at least know how to access that information. Education and resources should be offered based on needs identified from assessment.

### **Transition Readiness Assessment Questionnaire (TRAQ)**

Validated tool comprised of 20 questions which assesses self-care skills related to patient’s own health and ability to utilize health care services in 5 subcategories

- Managing medications
- Appointment keeping
- Tracking health issues
- Talking with providers
- Managing daily activities

Developing workflow processes in which the assessment tool is completed prior to the start of the visit (such as when patient in exam room waiting) can allow the patient to gain a sense of privacy as well as not feel rushed. The TRAQ can be used as a discussion tool to plan disease and skill-building education.

Patient Name: \_\_\_\_\_ Date of Birth: \_\_\_/\_\_\_/\_\_\_ Today's Date \_\_\_/\_\_\_/\_\_\_ (MRN# \_\_\_\_\_)

### Transition Readiness Assessment Questionnaire (TRAQ)

**Directions to Youth and Young Adults:** Please check the box that best describes **your** skill level in the following areas that are important for transition to adult health care. There is no right or wrong answer and your answers will remain confidential and private.

**Directions to Caregivers/Parents:** If your youth or young adult is unable to complete the tasks below on their own, please check the box that best describes **your** skill level. **Check here** if you are a parent/caregiver completing this form.

	No, I do not know how	No, but I want to learn	No, but I am learning to do this	Yes, I have started doing this	Yes, I always do this when I need to
<b>Managing Medications</b>					
1. Do you fill a prescription if you need to?					
2. Do you know what to do if you are having a bad reaction to your medications?					
3. Do you take medications correctly and on your own?					
4. Do you reorder medications before they run out?					
<b>Appointment Keeping</b>					
5. Do you call the doctor's office to make an appointment?					
6. Do you follow-up on any referral for tests, check-ups or labs?					
7. Do you arrange for your ride to medical appointments?					
8. Do you call the doctor about unusual changes in your health (For example: Allergic reactions)?					
9. Do you apply for health insurance if you lose your current coverage?					
10. Do you know what your health insurance covers?					
11. Do you manage your money & budget household expenses (For example: use checking/debit card)?					
<b>Tracking Health Issues</b>					
12. Do you fill out the medical history form, including a list of your allergies?					
13. Do you keep a calendar or list of medical and other appointments?					
14. Do you make a list of questions before the doctor's visit?					
15. Do you get financial help with school or work?					
<b>Talking with Providers</b>					
16. Do you tell the doctor or nurse what you are feeling?					
17. Do you answer questions that are asked by the doctor, nurse, or clinic staff?					
<b>Managing Daily Activities</b>					
18. Do you help plan or prepare meals/food?					
19. Do you keep home/room clean or clean-up after meals?					
20. Do you use neighborhood stores and services (For example: Grocery stores and pharmacy stores)?					

© Wood, Sawicki, Reiss, Livingood & Kraemer, 2014

[https://carma.massgeneral.org/clinical\\_topics/transitions/TRAQ5.pdf](https://carma.massgeneral.org/clinical_topics/transitions/TRAQ5.pdf)

## **TRANSITION PLANNING (AGE 14 – 18)**

- Develop and regularly update transition care plan, including readiness assessment findings, youth’s goals and prioritized actions.
- Maintain a brief medical summary with basic information such as such as allergies, surgeries and medications can be easily shared with new providers and specialists (could be maintained in EHR).
- Prepare youth and parent/caregiver for an adult approach to care and the optimal timing of transfer.
- Assist youth in identifying an adult clinician and provide insurance resources, self-care management information, and community support services.
  - Sample Care Plan from Got Transition’s “Transitioning Youth to an Adult Health Care Clinician”  
<https://www.gottransition.org/6ce/?leaving-plan-care>
  - Sample Medical Summary from Got Transition’s “Transitioning Youth to an Adult Health Care Clinician”  
<https://www.gottransition.org/6ce/?leaving-medical-summary-emergency-plan>

## **TRANSFER OF CARE (AGE 18-21)**

Providers should complete and share the transfer package (use Transfer Checklist to confirm all items are in EMR) with adult provider and patient. To optimize patient outcomes, young adult should be transitioned when their condition is as stable as possible.

- Sample Transfer Checklist from Got Transition’s “Transitioning Youth to an Adult Health Care Clinician”  
<https://gottransition.org/6ce/?leaving-transfer-checklist>

**THE SIX CORE ELEMENTS OF HEALTH CARE TRANSITION™ 3.0**

## Sample Transfer of Care Checklist

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*Preferred name*


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*Legal name*


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*Date of birth*


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*Primary diagnosis*


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*Social/Medical complexity information*
**TRANSFER OF CARE**

Prepared transfer package including:

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*Date*

- Transfer letter, including date of transfer of care
- Final transition readiness assessment
- Plan of care, including transition goals and prioritized actions
- Medical summary and emergency care plan
- Guardianship or health proxy documents, if needed
- Condition fact sheet, if needed
- Additional clinician records, if needed

Sent transfer package

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*Date*

Communicated with adult clinician about transfer

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*Date*


**Transitioning Youth to an Adult Health Care Clinician**  
Six Core Elements of Health Care Transition™ 3.0

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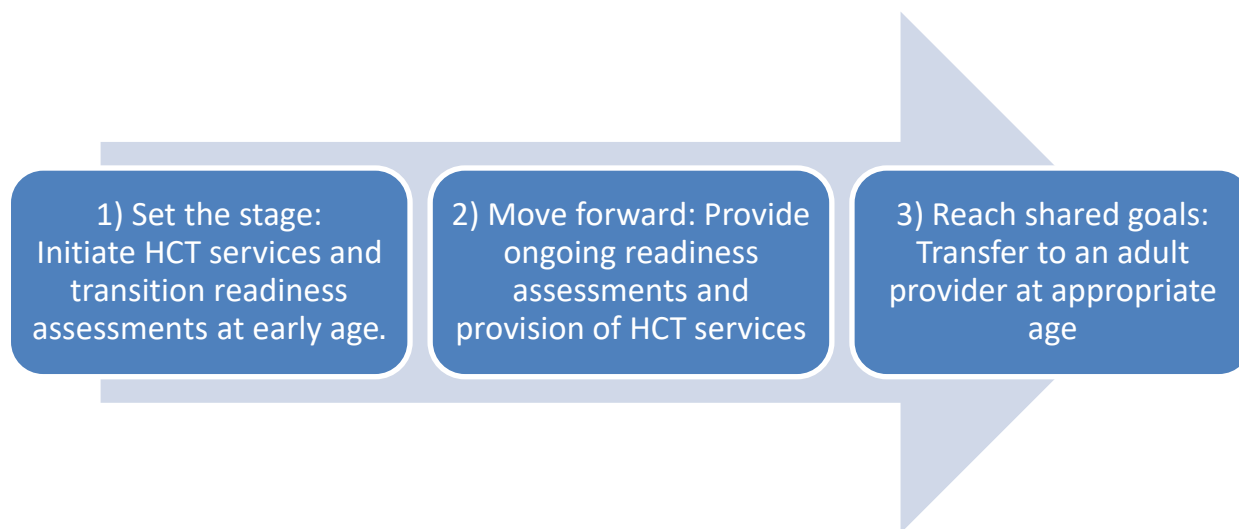


## 6. TRANSITION COMPLETION (AGE 18-23)

Confirms the end of the primary care pediatric role and establishes the beginning of care by an adult provider. The pediatric provider becomes a consultant if necessary. The pediatric provider should communicate with adult practice to confirm completion of transfer.

### Recommended Health Care Transition Timeline

AGE:	12	14	16	18	18-22	23-26
	Make youth and family aware of transition policy	Initiate health care transition planning	Prepare youth and parents for adult model of care and discuss transfer	Transition to adult model of care	Transfer care to adult medical home and/or specialists with transfer package	Integrate young adults into adult care



## BENEFITS OF A STRUCTURED APPROACH

### PATIENT OUTCOMES

- Enhanced self-management skills and self-esteem
- Improved access to care through referral of qualified providers
- Increased confidence in their team of providers
- Continuity of care - decrease in ER visits, hospitalizations, & school absences

### PARENT/CAREGIVER OUTCOMES

- Improved satisfaction with team communication
- Decreased anxiety and frustration
- Sense of partnership with professionals

### PRACTICE/SYSTEM OUTCOMES

- Better documentation and transmission of information
- Enhanced interprofessional collaboration and communication
- More cost-effective use of resources
- Improved communication and coordination of care



**\*Complete Transition Package linked below. All items are free and customizable. Use what works for your practice and add MGH logos\*.**

<https://www.gottransition.org/6ce/?leaving-full-package>



## **ADDITIONAL RESOURCES FOR PROVIDERS:**

Condition-Specific Tools from the American College of Physicians are available for the following subspecialties: general internal medicine (intellectual/developmental disabilities and physical disabilities), cardiology, endocrinology, gastroenterology, hematology, nephrology, and rheumatology.

Coding and Reimbursement Tip Sheet. Got Transition and the American Academy of Pediatrics developed a transition payment tip sheet to support the delivery of recommended transition services in pediatric and adult primary and specialty care settings. It provides a summary of alternative payment methodologies and comprehensive listing of transition-related CPT codes and corresponding Medicare fees (2020). Additional information on payment for services can be found here: <https://www.gottransition.org/six-core-elements/payment.cfm>

Letter Template to Payers Regarding Recognition of Codes Related to Pediatric to Adult Transition Services. A letter template to payers requesting recognition of transition-related codes. Edit and personalize in a PDF or copy and paste into a Word document to edit and personalize, from Got Transition (2017).

## RESOURCES FOR PATIENTS & FAMILIES

### **Got Transition Family Toolkit: Pediatric-To-Adult Health Care Transition:**

Toolkit developed for families to use during pediatric to adult HCT and includes resources for both parents/caregivers and youth/young adults.

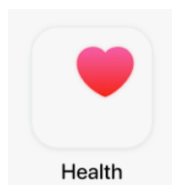
<https://www.gottransition.org/resource/?hct-family-toolkit>



### **MyMedSchedule Plus:**

A mobile app designed to give patients and caregivers access to their medication schedules anywhere they go. Patients can add multiple providers to their care team and receive updated medication schedules from each of their providers all in one place. The app can also automatically provide medication reminders.

<https://medactionplan.com/mymedschedule/>



### **Medical ID:**

Patients can set up their Medical ID in the Health app their cellphones. Here are the resources to help:

<https://support.apple.com/en-us/HT207021>

<https://www.gottransition.org/resource/?setting-up-medical-id-smartphones>

## **MYHEALTH 3**

The MyHealth 3 provides some tips on how patients can describe their health and current needs in about three sentences.

<https://www.childrensmercy.org/siteassets/media-documents-for-depts-section/documents-for-your-visit/your-visit-three-sentence-summary-ah.pdf>



Patients can create a MyHealth Passport which is a customized, wallet-size card that gives them instant access to their medical information (can be used when patients visit a new provider or visit an emergency room).

<https://wapps.sickkids.ca/myhealthpassport/Default.aspx>

### **Health Care Coverage Requirements**

- [HealthCare.gov](http://HealthCare.gov) is an interactive Web site that explains coverage options that are now available to patients through the Affordable Care Act. Patients apply online for private insurance coverage at the Health Insurance Marketplace. A Spanish language version of the site is at [www.CuidadodeSalud.gov](http://www.CuidadodeSalud.gov).
- The [National Disability Navigator Resource Collaborative](#) was designed specifically to assist people with disabilities identify insurance coverage options.

### **General College Health Information**

<https://youngmenshealthsite.org/guides/college-health/>