

APA GUIDELINES for Psychology's Role in Pediatric to Adult Health Care Transition

APA ADOLESCENT AND YOUNG ADULT TRANSITION TASKFORCE

APPROVED BY APA COUNCIL OF REPRESENTATIVES
AUGUST 2025



**AMERICAN
PSYCHOLOGICAL
ASSOCIATION**



Acknowledgements

The *Guidelines for Psychology's Role in Pediatric to Adult Health Care Transition* is the work of the Adolescent and Young Adult Transition Taskforce, part of American Psychological Association (APA) Division 54: the Society of Pediatric Psychology. Comprised of several groups of individuals, the Taskforce began its development in 2021 and continued with updates and revisions through 2025. In alphabetical order by last name, the Taskforce included Kristin Bingen, PhD; Frances Cooke, BA (Co-Chair); Lori Crosby, PsyD; Katie Devine, PhD; Michelle Eakin, PhD; Jordan Marchak, PhD; Siddika Mulchan, PsyD (Co-Chair); Ahna Pai, PhD; Jerlym Porter, PhD; and Lisa Schwartz, PhD (Co-Chair). The Taskforce acknowledges the APA Practice staff who facilitated the review of this document in accordance with APA Association Rules, including Mary G. Hardiman, MS, and Robin McLeod, PhD, and APA boards and committees that provided relevant and valuable input, including the APA Board of Professional Affairs and Committee on Professional Practice and Standards. Additionally, the Taskforce would like to acknowledge Patience White, MD, and Margaret McManus, MHS, for their guidance and expertise in the initial development of these guidelines.

Copyright © 2025 by the American Psychological Association. This material may be reproduced and distributed without permission provided that acknowledgment is given to the American Psychological Association. This material may not be reprinted, translated, or distributed electronically without prior permission in writing from the publisher. For permission, contact APA, Rights and Permissions, 750 First Street, NE, Washington, DC 20002-4242.

Suggested Citation

American Psychological Association, APA Adolescent and Young Adult Transition Taskforce. (2020). *Guidelines for Psychology's Role in Pediatric to Adult Health Care Transition*. Retrieved from <https://www.apa.org/about/policy/guidelines-pediatric-adult-health-care-transition.pdf>



AMERICAN
PSYCHOLOGICAL
ASSOCIATION

APA Guidelines for Psychology's Role in Pediatric to Adult Health Care Transition

APA ADOLESCENT AND YOUNG ADULT TRANSITION TASKFORCE

APPROVED BY APA COUNCIL OF REPRESENTATIVES, AUGUST 2025

TABLE OF CONTENTS

Introduction	1
The Guideline Statements	5
Transition Statement or Guide	6
Appendix A: Abbreviations, Key Terms, and Definitions	15
References	17

Introduction

About 20% of children and adolescents have a chronic health condition, and most of these children will survive into adulthood, according to the National Survey of Children's Health (Child and Adolescent Health Measurement Initiative, 2023). These youth face challenges assuming greater responsibility for their health and navigating the health care system (Mulye et al., 2009), as they must transfer from pediatric to adult care through a process known as health care transition (HCT; Schwartz et al., 2013). During this process of transitioning to adult-focused medical care, the goal is for the patient to develop more autonomy and maturity to manage their health and prepare for engaging in adult-oriented health care systems (Schwartz et al., 2013). Ideally, it involves collaboration among the patient, caregiver(s), and multidisciplinary health care team members, including psychologists, representing pediatric and adult medicine (White et al., 2018).

The complexity of the HCT process calls attention to the role of psychologists, given their competencies and various areas of expertise (Brown et al., 2002). Psychologists have increasingly become part of HCT programs to provide assessment, intervention, and consultation/coordination, as well as to conduct research, program development, and quality improvement (Gray et al., 2015). Given studies demonstrating that a structured HCT process can improve health outcomes for adolescents and young adults (AYAs) with medical conditions (Gabriel et al., 2017; Schmidt et al., 2020), these Professional Practice Guidelines seek to provide psychologists working with this population a foundation for best practices in supporting these youth and their families during the HCT process.

Several identified barriers associated with the HCT process include relationships among patients, parents, and health care providers; beliefs, expectations, and knowledge of self-care management and the HCT process; and challenges with access to health care services and health insurance (Gray et al., 2018). To address these barriers and inform the transition process, leading medical groups have published clinical guidelines highlighting the crucial role of behavioral health services in transition care (Leeb et al., 2020; McPheeters et al., 2014; White et al., 2018). However, none of these clinical publications specifically address the often-embedded role of psychologists within health care teams in the transition process. When physician-led groups develop or revise HCT guidelines, it is crucial that their development teams be multidisciplinary and include health psychologists.

The present guidelines are, in part, written to address that significant oversight, which is the lack of acknowledgment of the critical contributions of psychologists in HCT. These guidelines address this need by describing the important and varied roles of psychologists in applying these competencies during the HCT process through evidence-based practice, ultimately aiming to improve transition care and outcomes.

Psychologists may improve population health by targeting adherence, patient-reported outcomes, and self-care management skills (APA, 2022; Prior et al., 2014). For example, primary care programs integrating physicians and psychologists have significantly improved behavioral outcomes and reduced family distress among children (Kolko et al., 2014). Similarly, care collaboratives for adolescents with depression have found greater improvements in depressive symptoms and increased patient engagement (Rapp et al., 2017). Coordination of care within a patient's medical home can support development during critical periods, such as the transition from childhood to adulthood (Asarnow et al., 2017), and psychologists can play an active and meaningful role in transition care teams. Indeed, a transition is most successful when health care teams utilize a coordinated, multidisciplinary approach to address the comprehensive transition-planning needs of AYAs with medical conditions (Sharma et al., 2018). For example, there is growing evidence that the inclusion of psychologists in primary and specialty care results in significant improvements in mental health, access to services, and clinical outcomes for patients and financial benefits for patients and practices (Asarnow et al., 2017; Bai et al., 2018). Psychologists also appear to improve patient access to and use of evidence-based interventions (Asarnow et al., 2017). Furthermore, physical and mental health conditions are highly comorbid among AYAs (Holland et al., 2023; Nibras et al., 2022), further underscoring the importance of psychologists in facilitating a comprehensive transition process.

Psychologists are well-positioned to support all stages of the HCT process for AYAs, their families, and health care systems. There are specific roles for psychologists working in medical settings or who receive clinical health training. Clinical health psychologists have special training to provide developmentally and culturally responsive care and conduct research in health care settings. Clinical health psychologists also have expertise in understanding how individual, environmental, and developmental factors interact with and influence health and illness. Pediatric psychologists receive the aforementioned training with a specific emphasis on conducting clinical work and research for children and adolescents. This knowledge is critical during adolescence and young adulthood, when identity formation, goals, and the many influential systems of family, school, and peers are continuously changing. A core training competency of pediatric psychologists (who work in pediatric health settings) is knowledge of the transition of pediatric patients to adulthood and adult-oriented care (Palermo et al., 2014).

Furthermore, mental illness is most prominent in AYAs relative to any other demographic (age, gender, race/ethnicity). More than 1 in 4 AYAs are reported to have a mental, emotional, behavioral, or developmental problem (Child and Adolescent Health Measurement Initiative, 2023). Yet, many AYAs aging out of pediatric care are not connected with needed mental health treatment (National Institute of Mental Health, 2008; Child and Adolescent Health Measurement Initiative, 2023). The interaction between psychological and physical problems can obscure clinical decision-making regarding symptomatology, exacerbate disease, and influence its management (Hood et al., 2011; Herzer & Hood, 2010). For example, poor health promotion and adherence in adolescence may be influenced by depression (Hood et al., 2011) and anxiety (Herzer & Hood, 2010), conflict with other desired behaviors and goals, cultural beliefs about the value of health and Western medicine, gender and age, and family functioning (La Greca & Mackey, 2009). Thus, there is a potentially high yet largely unrealized value in partnering with psychologists to support transition care needs. Psychologists are uniquely positioned to provide evidence-based culturally responsive assessment and treatment of psychological problems in medical settings.

The specific competencies of psychologists, including extensive training on human development and behavior, culturally responsive care, management of medical conditions, and research related to assessment, intervention, and program development, align psychologists with current best practices in HCT care (APA, 2017). For example, psychologists' competencies position them as appropriate coordinators of transition discussions with patients, families, and the multidisciplinary medical team. Psychologists' training may also be preparatory for assessing a patient's HCT readiness, facilitating transfer with adult care providers, and developing and implementing targeted interventions to address transition barriers and improve HCT outcomes. Moreover, psychologists integrated with medical teams can help ameliorate barriers and facilitate successful outcomes for the HCT process. Behavioral interventions have the potential to improve indicators found to be significantly associated with attendance in adult medical care, including promoting developmentally appropriate parent involvement, increasing AYA motivation for engaging in medical care, and improving AYA health communication skills (Monaghan et al., 2013; Szalda et al., 2017). To this end, psychologists have developed, implemented, and evaluated targeted programs for AYAs with chronic conditions preparing for adult-oriented health care. Results suggest that participation in these programs increases knowledge of disease self-care management and confidence in assuming more independent management for care with related improvements in medication adherence (Crosby et al., 2017; Fredericks et al., 2015; Gray et al., 2019; Schmidt et al., 2020). Psychologists' training also positions them to consider the impact of social determinants of health on HCT, which are conditions surrounding an individual that can incur vulnerabilities due to systemic failures. Therefore, these guidelines take on the essential task of including current

considerations regarding inequities in health care and the role of a psychologist's perspective in addressing social determinants in the HCT process.

APA Guidelines and Standards

"Guidelines" refer to recommended professional behaviors, endeavors, or conduct. Guidelines differ from standards which are mandatory and, thus, may be enforced; guidelines are not mandatory or exhaustive. Guidelines are aspirational; they aim to facilitate the development of the profession and to promote a high level of professional practice. These guidelines may not apply to every professional and clinical situation. Guidelines are not intended to take precedence over professional judgment based on the scientific and professional knowledge of the field (APA, 2002; amended 2010 and 2017, Std. 2.04).

Content and Scope

The primary intent of these guidelines is to educate and inform health and pediatric psychologists who would benefit from guidelines on how to successfully serve on multidisciplinary teams when working with AYAs with medical conditions to facilitate patient access to services, promote health equity, and support positive health outcomes during the HCT process. These guidelines do not include youth with physical/intellectual/developmental disability alone but rather focus on those with medical/health conditions that may have comorbid disabilities. These guidelines may also assist psychologists and others in leadership roles who advocate for expanded roles for psychologists within health care systems and in systematic changes to support this work. These guidelines may be used by non-pediatric psychologists (e.g., adult-focused health psychologists, geropsychologists, neuropsychologists, and applied organizational psychologists) in relevant contexts, such as collaborating with pediatric psychologists. Lastly, other non-psychologist health care professionals may use these guidelines to understand and include the role of psychologists in the process of transitioning from pediatric to adult-oriented care more adequately. While specific components of these guidelines may be more or less relevant for each of the aforementioned groups, the Taskforce believes that the guidelines, as a whole, are essential for all groups to understand the vital benefits psychologists bring to HCT.

These guidelines describe considerations for comprehensive patient care, such as developing transition databases or implementing targeted interventions, which require practical resources and institutional and financial support. Therefore, it is essential to recognize the potential barriers present that may prevent implementation of the guidelines described below, particularly in settings with limited resources or infrastructure.

Development Process

The Division 54 Adolescent and Young Adult Transition Taskforce developed these guidelines. Taskforce participants received no financial support for this project, nor will they derive any financial benefit from the review, approval, or implementation of these guidelines. In the effort to be inclusive and comprehensive, the Taskforce invited and incorporated feedback from a variety of subject matter experts. As is customary, the guidelines also underwent a 60-day public comment process, during which the public could provide written comments. The Taskforce made substantive changes to the guidelines to address this feedback. The Taskforce selected, reviewed, and included the background literature for these guidelines based on seminal and recent peer-reviewed publications regarding clinical practice, research, advocacy, and policy within psychological science and HCT. Of note, a systematic literature review, including formal inclusion and exclusion criteria, was not conducted. However, the references included reflect primarily publications from the past 10 years to highlight a breadth of recent studies.

Moreover, the Taskforce did not receive external funding to assist with the preparations of these guidelines, meetings, or for conducting the literature review. No funds, grants, or other support were received for the development of this project, other than what was allocated in support of APA Boards and Committees to meet and develop guidance. The Taskforce's developers complied with APA's policy on conflicts of interest.

Expiration

This document is scheduled to expire in 2035, 10 years from the date of approval by APA Council of Representatives. After this date, users are encouraged to contact APA Practice to confirm that this document remains in effect.

Guidelines for Psychology's Role in Pediatric to Adult Health Care Transition

The Guideline Statements

Overview of the Guidelines

The *Guidelines for Psychology's Role in Pediatric to Adult Health Care Transition* offers ten guidelines organized according to the *Six Core Elements of Health Care Transition* (trademarked by Got Transition®, a program of the National Alliance to Advance Adolescent Health) which comprise the basic components of a structured transition process (White et al., 2020). This framework represents best practices in the field of HCT, which several leading professional organizations have widely adopted (White et al., 2018). Additionally, these guidelines are grounded in the Ethical Principles of Psychologists and Code of Conduct (APA, 2002; amended 2010 and 2017).

Transition Statement or Guide

GUIDELINE 1

Psychologists aim to develop, discuss, and share a transition statement or guide with AYAs and families.

Rationale

Transition statements or guides facilitate shared goals around transition that may be discussed and monitored. Transition statements provide a set of clear expectations for patients and their caregivers about the longevity of their relationship with the pediatric provider. Without an explicit transition statement that details planning and discussion, patients and families may expect life-long care from the pediatric provider and/or be mistrustful or fearful about the transition process (Leeb et al., 2020). Transition guides are roadmaps that inform youth and families about the intended timing and approach for the transition process, including consent and privacy protections for mental health concerns and treatment, changes when the patient turns 18, and other transition procedures. Such guides may include key milestones to assess individual progress toward transition readiness and may facilitate the equitable implementation of transition procedures (Roberts et al., 2020). Developmental, behavioral, cultural, and family factors are important to consider in the development of patient and setting (clinic)-specific transition guidelines (Anikputa & Horner, 2023; Ellison et al., 2022; Suris et al., 2004). Specific timing may vary, but conversations with patients and families regarding transition can occur as early as ages 12 to 14 (White et al., 2020).

Independent scholarly reviews and empirical articles recommend early and gradual collaborative transition planning that includes: (a) routine assessment of the AYA's developmental level and

readiness for transition; (b) evaluation and treatment of emotional functioning in transition-age youth, including potential anxiety related to transition; (c) promotion of youth disease self-care management; and (d) shifting responsibility for health care management (e.g. making appointments, refilling prescriptions) from parents to AYAs (Cooley et al., 2011; Sharma et al., 2018; White et al., 2018). Each of these recommendations seek to address emotional, behavioral, and relational issues in the context of a medical condition and health care setting.

Application

Psychologists may engage in the development of setting clinic-specific transition guidelines that are consistent with the specific health care and self-management needs of their particular patient population and work in collaboration with other psychologists throughout the health system. The guidelines may include considerations regarding how to monitor the developmental and behavioral conditions that influence the HCT process, shared goals, and progress. This guide may facilitate shared goals around transition that can be discussed and monitored. The guide aims to set clear expectations with patients about the longevity of their relationship with the pediatric provider. Without such planning and discussion, patients and families could wrongly expect life-long care from the pediatric provider and/or be mistrustful about the transition process. Further, when there are roadmaps to guide the transition process for the patient, family, and medical team that name the clear milestones used to assess individual progress toward transition readiness, the transition procedures may be more accessible, consistent, and equitable for all AYAs.

The clinic-specific transition statement and guidelines can be shared with each patient and appropriate family members and may include a description of how the clinic's transition policies apply to a specific patient. For most specialties, this might include sharing that patients do not stay with their pediatric providers indefinitely and the importance of transitioning to an adult provider for optimal care. Clinic-specific guidelines may provide standardized transition care for all patients and their families to reduce inequities across patients and help patients and families be informed of the transition readiness goals. A listing of the available multidisciplinary services in their specific health system and how those services could assist patients and families in each element of transition care is also encouraged. This ensures families are aware of the resources available to them and where to seek support for specific transition needs (Cooley et al., 2011; Sharma et al., 2018; White et al., 2018).

GUIDELINE 2

Psychologists strive to develop and implement a system to track and monitor progress during the transition process for AYA.

Rationale

Previous research has shown that (White et al., 2020; White et al., 2018), the transition process is gradual and ideally conducted over time, beginning in adolescence and continuing into young adulthood. The treatment team aims to monitor patients' receipt of transition services (e.g., policy, readiness assessment, medical summary) as well as progress and achievement

of milestones for AYAs and families. Psychologists are well-trained to develop systems to identify milestones of progress and evaluate outcomes related to patient changes in indicators of transition readiness (Palermo et al., 2014). These practices are consistent with best clinical practices to establish and measure clear transition goals (Cooley et al., 2011; Davidson et al., 2022). A tracking system is essential to gauge individual patient progress and to set collaborative goals. Transition plans and supports may be adjusted based on documented progress and barriers. Data from the tracking system may also be used to evaluate the collective progress and barriers for transitioning youth at a group/practice level. In turn, this information could facilitate improvements in clinical care at the setting/practice.

Application

Psychologists may collaborate with multidisciplinary transition teams to develop a transition registry or database that would identify and track salient, measurable transition goals or milestones as well as barriers. When clinics establish tracking systems, they may include an agreement on transition services offered by the practice as well as relevant milestones, goals, patient characteristics, and outcomes to track. The system could track outcomes after the transfer of care and records of patient referrals, including whether referral follow-throughs took place. This information helps to evaluate the success of the transition process from start to finish. The tracking system would ideally store data in a password-protected, modifiable format that allows updates with new information from patient visits and assessments. Psychologists using a tracking system, as described, must ensure the protection of sensitive patient information (APA, 2002; amended 2010 and 2017).

GUIDELINE 3

Psychologists aim to assess self-care management skills and offer education on identified needs for AYA and families.

Rationale

There are multiple domains of functioning (e.g., disease-specific, individual, family, and environment) associated with self-care management and HCT. Psychologists are well-suited to understanding and identifying the barriers and facilitators that contribute to transition readiness. Psychologists are well-trained in instrument development and psychometrics and may contribute to routine evaluation and monitoring of self-care management skills and transition readiness needs as youth mature and make developmental progress. Psychologists strive to consider individual characteristics, such as language, culture, disability, and role differences, and describe the strengths and limitations of the assessment tools that may impact the interpretation of results (APA, 2002; amended 2010 and 2017).

The assessment of self-care management behaviors in AYA and families may help to determine the needed skills and competencies an individual and family needs to successfully navigate the transition. The results of the assessment might then guide the use of targeted interventions and resources aimed at facilitating a successful transition from pediatric to adult-based health care. Research has shown that educational and supportive interventions designed to improve self-care management have shown promise in contributing to improved health outcomes, such as increased quality of life, physical functioning, disease-related knowledge, medication adherence, and decreased health service utilization (Kirk et al., 2012; Lindsay et al., 2014).

Application

Psychologists can make recommendations to the transition team regarding evidence-based, developmentally appropriate assessment tools to evaluate targeted transition variables or constructs. They can also lead on analyzing and interpreting assessment results for the transitioning patient. Specifically, psychologists are competent to complete cognitive and psychological testing and interpret test results in the context of the patient's medical condition and treatment. Assessment of an adolescent's intellectual functioning, adaptive behaviors, and executive functioning can provide valuable information to the transition team regarding an adolescent's developmental maturity and functional abilities, which directly impact a patient's ability to move towards autonomy, independently execute disease-specific tasks, and/or navigate the health care system in adulthood. Other areas for assessment may include mastery in various targeted skill-based health behaviors (i.e., medication adherence) and health care utilization (i.e., self-advocating for one's health). Psychologists have contributed to the evaluation of existing measures of transition readiness (Schwartz et al., 2014) and toward establishing a few validated general transition readiness measures (see systematic review, Parfeniuk et al., 2020). Based upon critical cut-off scores or significant changes indicating declines or lack of progress in the targeted transition constructs measured, psychologists can collaborate with the team to implement and develop interventions that promote improvement in the identified domains, and/or provide accommodations and supports for those with significant adaptive behavior difficulties. Findings from assessments can also be used for education, counseling, and identifying transition self-care skill priorities.

GUIDELINE 4

Psychologists strive to engage all appropriate individuals and communities of interest (e.g., patients, families, and medical teams) in developing a health care transition plan with a medical summary for each AYA.

Rationale

The development of an HCT plan is a key component for successful transition for youth with special health care needs and is often a component of structured transition programs or interventions (Gabriel et al., 2017; Schmidt et al., 2020). An HCT may include goals of care, medical summary, and interventions and resources to support transition as needed. HCT plans are tailored to individual goals and consider cultural preferences and family values. Psychologists often work in multi-disciplinary teams that include patients and families. Psychologists strive to facilitate communication amongst professionals across varied disciplines and serve as the communication liaison between patients/families and the medical team. Psychologists may be instrumental in communicating a patient's transition needs, preferences, and goals throughout the process of developing an HCT plan.

Application

Psychologists may work collaboratively with identified pediatric and adult health care teams, patients, and families to facilitate medical teams to develop written transition plans that include a medical summary, including mental or behavioral health issues. The transition plan is ideally ready to share with the family well ahead of the transfer which works as a "living document" that evolves as the patient continues in pediatric care. A medical summary is a written document that may include information about diagnoses; the current treatment plan, including an up-to-

date medication list with dosages and frequency of administration; health care specialists involved in managing care; as well as information about past treatments as appropriate. Medical summaries may also briefly describe previous surgeries, hospital admissions, and other events in the AYA's clinical course that may be helpful for new adult providers to know.

Along with the medical summary, the HCT plan should identify the patient's goals and values for treatment. Transition goals should be developed in partnership with the patient and family to ensure that their voices are included and to incorporate all gender/sexual identity, cultural, or religious preferences. Once the patient's goals are developed, the HCT plan may list specific activities/tasks and milestones to facilitate the development and monitoring of an AYA's transition to independent self-care management and other related goals. Expressed skills and milestones within the HCT plan may identify who might be responsible in providing support, resources, and education if needed and dates for monitoring to track progress. The skills and activities/tasks may be unique for the patient's self-care management needs, diagnoses, and treatment plan. Some examples of skills and activities monitored may include a patient's level of self-efficacy in disease management skills (van Staa et al., 2011), social support (Haas et al., 2010; Idalski Carcone et al., 2011), psychological functioning (Baskin et al., 1998), family functioning (Holmbeck & Devine, 2010), social determinants of health (Rodriguez et al., 2023; Syed et al., 2021), and self-care beliefs (Sawicki et al., 2014) that may impact transition (Rosenberg-Yunger et al., 2013). HCT plans may also address potential legal issues that can occur when adolescents become adults and if additional specific steps to ensure adequate planning are needed. For example, the HCT plan may include advance care plans, extended legal guardianship, etc.

Psychologists may consider creating two versions of the transition plan:

one tailored to the patient's level of understanding and family needs (e.g., language, health literacy, visual abilities), and the other containing the comprehensive medical summary catered to future adult physicians. Ideally, the HCT plan would be part of the patient's electronic medical record (EMR) and transfer along with the patient's medical records to the adult health care provider(s) in adherence to Health Insurance Portability and Accountability Act (1996) guidelines to facilitate a seamless and ethical transition of care.

GUIDELINE 5

Psychologists endeavor to be familiar with the relevant frameworks, research, and practice of evidence-based interventions for AYA that are more likely to facilitate effective transition planning.

Rationale

The practice of psychology with AYA strives to implement interventions that are designed to promote lifelong health and target a variety of physical and psychological symptoms. Evidence-based intervention in the context of health care often includes prevention, treatment, psychotherapy, and consultation (APA, 2025). Becoming familiar with relevant frameworks and research related to the practice of HCT interventions may assist psychologists in providing high-quality clinical services that address AYA's unique physical and mental health needs during a move from pediatric to adult care.

HCT frameworks may assist psychologists to generate robust conceptualizations and treatment plans during their clinical care of AYA. In addition to the typical individual and socioecological factors considered when working with youth without

medical conditions, interventions for AYAs with medical conditions are encouraged to be conceptualized and applied within the context of each AYA's health, disease, disability, and medical setting. Psychologists are uniquely poised to take an active role in preparing AYAs for HCT through services targeting health self-care management, self-advocacy, and skill-building targeting health care behaviors because of their expertise in health behavior change. Also, psychologists may design and implement HCT interventions to address noted gaps in the availability of evidence-based interventions (Hart et al., 2019; Levy et al., 2020).

Application

Several frameworks may help psychologists to provide clinical care to AYAs with medical conditions. Schwartz and colleagues developed the Social-Ecological Model of Adolescent and Young Adult Readiness to Transition (SMART), an empirically based, theoretical framework for AYAs (Schwartz et al., 2011; Schwartz et al., 2013). The SMART model addresses preexisting factors that may impact transition success but are less amenable to behavioral interventions (i.e., sociodemographic variables/neurocognition and general cognition/intellectual and developmental disability, etc.), as well as more modifiable variables that may be beneficial targets for intervention to improve transition outcomes (i.e., knowledge, skills/self-efficacy, beliefs/expectations, psychosocial/emotions, etc.). The SMART model has recently been updated for youth with sickle cell disease, with plans to validate it with samples of AYAs in other disease groups. The updated model, referred to as SMART-E ("E" for "to Promote Health Equity"; Prussien et al., 2024), incorporates additional constructs relevant to HCT potentially including systems of power and health literacy to highlight the need to address disparities and address equity in the transition process.

The Health Care Transition Research Consortium (HCTRC) developed another theoretical HCT model. This model is comprised of four interrelated domains (e.g., Individual, Family/Social Support, Environment, and the Health Care System) that represent the ecological systems integral to research and practice with AYAs transitioning to adult care (Betz et al., 2014). The HCTRC HCT model specifies contextual variables within each domain that may serve as mediators or moderators of the impact of domains on the HCT process and eventual HCT outcomes. Another model, The Pediatric Self-Management Model, situates AYAs' self-care management behaviors within individual, family, community, and health care system domains (Modi et al., 2012). This model posits modifiable and non-modifiable factors that influence self-care management through cognitive, emotional, and social processes and describes bidirectional relationships between self-care management behaviors and outcomes.

The SMART framework, HCTRC HCT model, and Pediatric Self-Management Model are example frameworks that may assist psychologists in case conceptualization and treatment planning to prepare AYAs and their caregivers for eventual transfer to adult health care. The Transition of Health Care Responsibility Model incorporates the health self-care management literature in the proposed developmental systems conceptualization of the transition of health care responsibility from parents/caregivers to AYAs using a developmental systems perspective (Reed-Knight et al., 2014). The Transition of Health Care Responsibility Model may aid psychologists in identifying individual and dyad-level factors that influence the transition of health care responsibility and suggest strategies to AYAs and their caregivers that promote the successful transition of specific health care tasks.

As part of their clinical service delivery to AYAs, psychologists may actively work to help AYAs improve self-efficacy related to health self-care management through education and skill-building. Psychologists may teach interpersonal

effectiveness skills required for AYAs to best advocate for their health within adult-centered health care systems. Psychologists may assist with goal setting and problem-solving around the transition of health care responsibility from parent/caregiver to AYA. Also, psychologists may consider structuring behavioral opportunities to familiarize AYAs and their families with the demands of the adult system, such as planning "adult visits" within the pediatric system before transfer, where AYAs may practice calling to schedule appointments, checking themselves into and out of their visits, and speaking to providers without parents/caregivers present.

Psychologists can design, implement, and evaluate HCT interventions using theoretical frameworks to help AYAs obtain the knowledge and skills necessary to manage their health within the adult medical system, given their knowledge of behavior change interventions and clinical research competencies. For example, psychologists may use the Self-Management Transition Enhancement Program (STEP), which was developed to assist youth with inflammatory bowel disease in preparation for transfer to adult care through one in-person group session followed by four individual telehealth sessions (Gray et al., 2021). Or psychologists might better prepare AYAs with sickle cell disease for transition to adult care by using the Students Helping Individuals Facilitate Transition (SHIFT) program which was created to provide AYAs with 6-months of mentoring from medical students to enhance their disease knowledge, self-efficacy, self-care management, and communication skills (Viola et al., 2021). With AYA-aged survivors of cancer, psychologists might turn to an AYA self-care management program that uses texting, education, and plans for survivors (AYA STEPS) to improve their health-related knowledge and survivorship self-care management through a 16-week mHealth intervention (King-Dowling et al., 2021). Psychologists may use quality improvement methods to embed these professional practice

guidelines into their practices, guided by resources such as the *Six Core Elements* implementation guides. Psychologists in clinical practice and research are well-positioned to lead the development of interventions and increase the availability of evidence-based interventions that aid AYAs as they transition to adult care and promote improved transition outcomes.

GUIDELINE 6

Psychologists aim to facilitate AYAs' successful transfer to adult-centered care.

Rationale

Once a plan for transfer is in place, it is necessary to provide coordinated, flexible, and developmentally appropriate services to support patient (and their caregivers') agency in the uptake of adult care. Psychologists have expertise in the developmental and behavioral aspects of transition such as treatment adherence, patient-caregiver communication, adjustment and change of roles and responsibilities in the health care system, and normative behaviors of emerging adults. It is vital to inform and involve AYAs, parents/caregivers, and providers in the hand-off of care, alongside the timely communication of current medical information between pediatric and adult providers. A well-planned transfer of care to adult providers may facilitate optimal health outcomes for AYAs. Psychologists are competent to work within multidisciplinary care teams and serve as facilitators among all individuals and communities of interest in the transfer of process.

Application

Psychologists are encouraged to help patients and families be informed of and involved in the process of the transfer to adult care. To support patient

autonomy, psychologists may discuss with AYAs and families shared decision-making and the change in their roles and responsibilities in managing their health care. Psychologists are encouraged to address patient concerns about the transfer to new adult providers, the differences between pediatric and adult health care systems, and reactions to ending long-standing relationships well in advance of the transfer. It is recommended that psychologists discuss barriers and facilitators to treatment adherence to support self-care management skills. Psychologists strive to help patients create health care and personal goals and to facilitate communication and coordination between pediatric and adult providers. For example, psychologists may consult with and educate adult providers on typical pediatric experience and how the pediatric culture influences patient and family expectations. They can also ensure that the receiving adult providers have the current medical summary, recent transition readiness assessment, and plan of care. Psychologists can facilitate contact between AYAs and adult health care treatment resources and the transfer to adult behavioral health providers to prevent decrements in mental health functioning during this critical transition period (e.g., facilitating a joint telehealth call between pediatric and adult providers and the patient).

GUIDELINE 7

Psychologists strive to confirm transfer completion and elicit feedback on the transition process for AYAs and families.

Rationale

Psychologists are encouraged to confirm that the care for AYAs discharged from a pediatric provider has been transferred to an adult provider.

Treatment teams that confirm the transfer from pediatric to adult providers strive to follow the *APA Guidelines for the Psychological Practice in Health Care Delivery Systems* (APA, 2025), which encourages psychologists to engage in timely communication with other health care professionals to optimize care. Psychologists have the training, experience, and expertise to facilitate continuity of care and problem-solve in cases of a delayed or incomplete transition. More than one appointment with a health care provider may be needed to get to know the AYA and partner with them to provide better care. An important part of the HCT is ensuring continuous developmentally appropriate preventive care. Deficits in preventive care increase the risk of psychosocial and medical problems for AYAs and may compromise health outcomes in the future (Betz, et al., 2014). For example, AYAs who fail to obtain routine care may seek care for psychological or medical problems in the emergency room, placing them at risk for care inequities. Continuity of care is even more vital for AYAs with neurodevelopmental concerns who may be followed by multiple providers and require more coordination of care (Rachas, et al., 2016). To enhance patient care and promote health equity, psychologists strive to coordinate with and get feedback from the adult provider and other individuals and communities of interest (e.g., pediatric providers, AYA, family) about the transition process with the goal of mitigating any inequities that may potentially occur in the process.

Application

Psychologists are encouraged to confirm AYAs' transfer completion (i.e., establishing their health care within an adult medical home) through communication with the adult care team. Regardless of the setting in which they work, psychologists may engage in networking and community partnerships to build relationships with adult

providers and facilitate a warm handoff for transitioning AYAs. Psychologists may collaborate with health care teams to generate a medical summary of previous care for each patient (see Guidelines 4 and 6) ahead of the initial adult care appointment. This summary serves as a tool for the efficient transfer of health information from pediatric to adult care and may limit the need for patients to memorize their health history. At the final appointment before transfer, the pediatric provider may review and provide a written and electronic copy of the medical summary to the patient. Psychologists can also provide education to AYAs about the summary and role-play how to explain it to their adult provider (e.g., a document that includes “my health history” and current medications). When the adult care team receives the medical summary, they might send an electronic notification to the pediatric team to confirm that the patient attended their initial transfer appointment for better outcomes. Conversely, if the patient did not attend the initial adult appointment, the adult provider might directly communicate this fact to the pediatric team so that if the patient were to return to the pediatric health setting or contact the pediatric provider, the psychologist can take steps to attempt to effectively transition the patient again.

Additionally, psychologists strive to elicit feedback on the transition process from individuals and communities of interest to facilitate quality improvement. For example, the Got Transition® website has sample feedback surveys for AYAs and caregivers on the HCT process. Ideally, feedback—obtained from patients, caregivers, and health care providers (pediatric and adult)—would produce changes to improve the process. Data collected might be shared with both the pediatric and adult care teams to inform their processes and explore alternative approaches to optimizing the HCT process and experience for patients and caregivers. .

GUIDELINE 8

Psychologists strive to provide transition care that is socially and culturally relevant and within the context of social disparity and barriers to transition of care.

Rationale

It is important that pediatric to adult care transitions be considered within the cultural and social context of patients and their families. Principle E of APA’s Ethics Code (APA, 2002; amended 2010 and 2017) indicates that psychologists recognize and respect cultural and individual differences. This includes potential risks and vulnerabilities as well as resilience factors that impact transition (White et al., 2018), such as social determinants of health (SDOH), self-care management practices, family environment, and other psychosocial considerations (Lotstein et al., 2010; McKenzie et al., 2019). SDOH plays a critical role in achieving optimal health and wellness, particularly for AYAs (Tebb et al., 2018; Viner et al., 2012) and can impact transition preparation and success. Research has found that access to quality health care, insurance coverage, health literacy, and transportation may affect transition outcomes (McKenzie et al., 2019). The SMART model (Schwartz et al., 2013), which captures factors impacting transition readiness, highlights the role of sociodemographic variables and culture. Consideration of these variables in combination with the beliefs, values, and preferences of AYAs and families not only promotes a more holistic view of health but may also improve transition outcomes. A successful transfer to adult care increases when transition goals are consistent with family values and preferences (White et al., 2018). Moreover, failure to address the cultural, social, and familial barriers to transition heightens the risk of poor health outcomes, including early mortality, for AYAs (Hamideh & Alvarez, 2013).

Application

Psychologists strive to provide culturally relevant care and receive ongoing training in cultural humility, bias, and stigma in health care to prevent perpetuating health inequities, especially during the critical period of transition from pediatric to adult care. Given the importance of risk and protective factors in predicting health outcomes (Evans et al., 2013; Shonkoff et al., 2012), psychologists endeavor to assess patient and family risk and resilience in the context of transition to guide interventions and treatment planning. For example, AYAs presenting with poor adherence may demonstrate limited health literacy (risk factor) but strong family support (resilience factor) during a clinical interview. Psychologists are encouraged to identify and incorporate these factors into their case conceptualization (e.g., limited health literacy may lead to anxiety and avoidance unless a family member is present to provide support), treatment planning (e.g., individual psychoeducation and strategies to improve self-efficacy may be combined with family-based interventions to improve adherence), and the written health care transition plan. Once risk and protective factors have been assessed, psychologists attempt to help AYAs and their caregivers address potential barriers to transition success. If barriers exist outside of the role or boundaries of competence of psychologists, referrals are made to other disciplines or agencies, including social work, care coordination, case management, and outpatient behavioral health services. Given the multitude of factors affecting transition to adult care (Pai & Ostendorf, 2011), psychologists strive not to work in silos and instead engage in collaborative planning and ongoing communication with other health care providers and teams as is relevant to transition preparation, transfer of care, and integration into adult care.

Psychologists seek to understand how AYAs and their families’ previous experiences with discrimination,

negative patient-provider interactions (e.g., microaggressions), and lower quality of care may impede transition success (Tebb et al., 2018; Lotstein et al., 2010). Language that prevents blaming and de-humanization is an important factor impacting how health care teams perceive, interact with, and treat patients and families (Goddu et al., 2018). Therefore, psychologists strive to use inclusive language (APA, 2023), such as person-first (Dunn & Andrews, 2015) and systems-centered language (O'Reilly, 2020), during verbal and written communication with treatment teams and in conducting research. An example of person-centered language would be saying "a patient with sickle cell disease" instead of using terms that fuse the individual with their illness (e.g., sickler). Dr. Meagan O'Reilly, PhD provides recommendations for shifting to the use of systems-centered language when discussing individuals or groups experiencing oppression and/or racism. For example, rather than using the term "at risk" for marginalized groups, the recommendation is to describe these groups in other ways, such as "exposed to additional harm." Language may also lead to more or less favorable associations by providers (Goddu et al., 2018): AYAs who share plans for attending college may be viewed more positively than those who indicate they are unsure of their plans after high school. Therefore, psychologists are encouraged to highlight patient/family resilience (Ellis et al., 2017) when engaging in transition planning, rather than focusing solely on risk factors.

Several national organizations describe the structural racism and discrimination that might contribute to adverse health outcomes in children and youth (Abman et al., 2020; Trent et al., 2019). There are other SDOH and systemic factors (Tebb et al., 2018; Lotstein et al., 2010), including institutional policies and procedures (White et al., 2018; Wang et al., 2010), that may exacerbate existing health disparities for marginalized AYAs transitioning from pediatric to adult care. As such,

psychologists are encouraged to advocate for policies and practices that are responsive to the socio-cultural context affecting AYA health care transition. For example, the age at which AYAs must transfer to an adult medical home can affect transition outcomes (Wisk et al., 2015). When institutions have a younger cutoff age (e.g., 18 years), this policy may not consider the relevant socio-cultural factors related to the patient's self-care management skills, sense of belonging, and level of autonomy. Specifically, young patients from cultures that emphasize strong family relationships and involvement in care may feel abruptly uprooted from their pediatric team and inadequately prepared for the increased autonomy associated with adult-oriented medicine. Furthermore, AYAs undergoing multiple life transitions (e.g., finding a job, starting college or vocational school, moving out of the home, financial independence, etc.) with limited resources and support may face barriers and restrictions that could hinder transition success compared to youth with greater access to financial and social resources and support (Oswald et al. 2013). Psychologists seek to address these systemic issues through education, leadership, and policy development within their institutions. Through such advocacy, the consideration of social, psychological, and environmental factors may be integrated into institutional policies and procedures surrounding the transition to adult care.

Institutional policies and practices related to the HCT process may also inadvertently perpetuate negative stereotypes or attitudes toward certain patients and/or populations (Goddu et al., 2018; Sun et al., 2022). Negative patient descriptors, such as "noncompliant," in the EMR may exacerbate racial and ethnic health disparities (Sun et al., 2022). Additionally, the number of "no-show" visits may be highlighted in the EMR with no context as to the reason(s) for these data. Providers may develop negative perceptions of AYAs and their families with a high rate of

no-shows, which could subsequently impact patient-provider interactions (Goddu et al., 2018). Psychologists can work with their institution to identify these potentially discriminatory practices. The following brief vignette demonstrates how patients' social and cultural context could be incorporated into transition planning and transfer to adult care. A White, cisgender, female psychologist embedded within a pediatric hematology/oncology department has been working with a 17-year-old, Black cisgender male with sickle cell disease to improve his transition readiness. The patient's medical team referred him for concerns about his medication adherence. After the initial intake session with the patient and his mother, the psychologist learns that cultural factors affecting familial roles and responsibilities, as well as financial stressors, are contributing to the patient's poor adherence. The patient describes being a secondary caretaker for his three younger siblings, as his mother must work to support the family, and their father died 2 years ago. The patient also works part-time while completing his senior year of high school. The patient reports symptoms of stress and anxiety due to the multiple demands for his time and attention (i.e., family, work, and school). The psychologist documents and verbally communicates relevant background information to the patient's medical team about factors affecting the AYA's adherence and collaborates with social workers to provide family resources and support to distribute the patient's responsibilities. The psychologist also advocates for delaying the patient's transfer to adult care another year until his self-care management skills improve.

GUIDELINE 9

Psychologists strive to meet professional practice guidelines and Ethical Standards throughout the entire duration of transition services provided.

Rationale

AYAs and their families ideally receive the highest quality of psychological care throughout the entire duration of transition services. Consistent with the general principles of the APA Ethics Code, psychologists strive to benefit those with whom they work, establish trusting relationships, practice with integrity, promote justice and equity, and respect the worth and rights of all persons (APA, 2002; amended 2010 and 2017). Particularly relevant to working with AYAs, psychologists aim to maintain the confidentiality of their work, including asking AYAs for consent to disclose confidential information to relevant individuals, such as parents, when the AYAs reach the legal age of majority. Psychologists also strive to uphold professional practice guidelines relevant to the provision of care with diverse individuals in multidisciplinary health care settings. Psychologists strive to communicate effectively with all care team members across relevant settings within the scope of their competencies (APA, 2025) because transition services may involve collaboration among professionals from different backgrounds or health care settings (e.g., pediatric and adult services).

Application

Psychologists are encouraged to obtain appropriate education, training, and consultation in the unique developmental needs of AYAs with diverse backgrounds to work competently with these youth during the transition process. Psychologists strive to maintain these competencies and uphold professional practice guidelines and Ethical Standards. Psychologists are encouraged to consider challenges associated

with the normative cognitive, emotional, and social development of AYAs, including challenges associated with specific health conditions (Bethell et al., 2014; Mattson et al., 2019) and any cognitive delays or deficits that may interfere with obtaining and maintaining informed consent. Further, psychologists aim to screen for, identify, and intervene in SDOH that may hinder positive health care transition outcomes. Psychologists aspire to communicate effectively and work collaboratively with other health care professionals to optimize care for AYAs and families.

Psychologists strive to be aware of, comply with, and inform patients and families of laws and resources relevant to this population, including local, state, and federal laws related to age of majority, supported decision-making, guardianship, conservatorship, and educational rights, for example, the informed consent laws within the Americans with Disabilities Act (1990). When working with AYAs and their families and guardians, psychologists strive to clarify who the patient is, the relationships among all relevant parties, and any limitation or disclosure requirements of confidential information within this context. As AYAs with medical conditions reach the age of majority to consent for their health care, psychologists are encouraged to stay alert of changes regarding guardians' legal involvement in youths' care and access to their health records. Psychologists are well-positioned to facilitate conversations with patients and families about legal rights to medical decision-making (e.g., advance care plans) and patient decision preferences. Psychologists are encouraged to seek ongoing continuing education to maintain competencies and be aware of any changes in local, state, or federal health care policies or standards that may affect their services to AYAs with medical conditions.

Considering the rise in the utilization of teletherapy, psychologists are encouraged to understand best practices for telepsychology, for example, the *APA Guidelines for the*

Practice of Telepsychology (APA, 2024). Psychologists aim to follow professional practice guidelines regarding the delivery of telepsychology services, informed consent, confidentiality, data security, and interjurisdictional practice. Telemedicine has the potential to increase the convenience of appointments and access to care for those with geographic, transportation, and other barriers. For example, adult providers may be introduced to patients and families virtually during transition appointments. However, psychologists strive to be aware of individual preferences for services, as some AYAs have expressed their preference for in-person visits and concerns about the confidentiality of telemedicine visits (Barney et al., 2023). Telemedicine may allow for a psychologist to maintain contact with the AYA as they transition to adult provider(s) to enable the psychologist to confirm the successful transfer. Working in settings that utilize EMRs, such as health care systems, psychologists endeavor to follow codes of conduct for confidentiality and aim to inform patients and families about the protection of confidential information and the extent to which records are available to families and other providers. Psychologists may help facilitate the patient by providing family access to health information in contexts where patients desire parents' ongoing involvement and access to health information after the patient is legally an adult.

GUIDELINE 10

Psychologists seek to comply with public policy, state, and federal laws and regulations relevant to the provision of and reimbursement for psychological services related to AYA health and transition of care.

Rationale

Psychologists seek to understand and comply with public policy, laws, and other regulations related to AYA health, transition of care, and the provision of psychological services. While not all psychologists directly advocate for changes in public policy, it is encouraged that they seek comprehensive awareness and support of extant policies. This is due, in part, because public policy and laws change based on a patient's age. It is important to be aware of these changes throughout the care for a patient, as these regulations are likely to change while the patient receives health care services or transitions to adult care.

The transition from pediatric to adult care intersects with transitions across several social, emotional, and cognitive domains of a young adult's life (Tsang et al., 2022). Psychologists working with AYAs during transition periods are encouraged to adhere to public policy and state and federal laws to advocate for needed services. If an AYA experiences challenges or barriers in one domain of life, they may likely struggle with others (Byrne et al., 2007; Karyotaki et al., 2020; Roy et al., 2015). Psychologists working with AYAs seek to be aware of patients' transition rights outlined in state and federal laws. Furthermore, psychologists are encouraged to gain sufficient knowledge of the regulations relevant to the provision of and reimbursement for psychological services related to AYA health and transition of care. Got Transition® and the American Academy of Pediatrics partnered on two reports (McManus et al., 2018; White et al., 2018) encouraging payment approaches to support the delivery of transition services and offering guidance with patient vignettes. Appropriate reimbursement for psychological services throughout the transition process is critical at the patient, provider, and systems levels. For instance, compliance with reimbursement regulations allows families to utilize insurance benefits and avoid unnecessary costs for services. When psychologists strive

to document and adhere to reimbursement regulations for psychological services related to transition of care, additional benefits include institutional sustainability of effective transition of care interventions.

Application

Psychologists are encouraged to obtain continuing education regarding institutional policies and laws that are relevant to the provision of and reimbursement for psychological services related to AYA health care transition. If feasible and within the capacities of the institution or practice in which the psychologist is located, psychologists are encouraged to advocate to inform policy when there is no official guidance, or to update the extant policies based on current best practices. It is recommended that psychologists continuously take into consideration crucial factors of HCT health equity and social determinants of health and the impact of law and policy impact on them.

Beyond familiarity with policy and law, psychologists are encouraged to build skills and experience in effectively communicating with patients, families, and health care providers about the role psychologists play in facilitating the transition to adult care. Throughout the transition process, it is essential to notify patients' families of the relevant laws and public policies that influence their child's care and rights and that they understand them. Psychologists interacting with AYAs play a key role in ensuring families understand the laws and policies concerning this transition period. Therefore, psychologists strive to be aware and inform patients and families of relevant policies and resources, such as those instituted by the Americans with Disabilities Act, as well as resources beyond health, such as vocational and educational access.

Abbreviations, Key Terms, and Definitions

- Adolescents and young adults (AYAs) refer to individuals ages 10–24 years (World Health Organization, 2024). Other national and international organizations have defined AYAs by various age ranges.
- **American Psychological Association (APA)**
- **Clinical health psychologists** are psychologists who have received specialized training in health psychology and the delivery of psychological services in health care settings.
- **Got Transition®** is the national resource center for HCT operated by The National Alliance to Advance Adolescent Health (<https://www.gottransition.org/>). It aims to improve the HCT process using evidence-based strategies for health professionals, youth, young adults, and their families. Got Transition® uses its *Six Core Elements* approach to define the basic components of a structured transition and provides free tools available online for each step of HCT. Got Transition® provides three tailored packages of transition tools and an implementation guide, depending on the circumstances of the transition: transitioning youth to an adult medical provider, transitioning to an adult approach to medical care without changing providers, and integrating young adults into adult health care.
- **Health care transition (HCT)**, according to Got Transition®, is the “process of moving from a child/family-centered model of health care to an adult/patient-centered model of health care, with or without transferring to a new clinician.” This process includes preparation on the part of patients and their support systems (e.g., parents, health care providers, school personnel), transfer, and integration into adult health care.
- **Health Care Transition Research Consortium (HCTRC)**
- **Health disparities** are “preventable differences in the burden of disease, injury, violence, or opportunities to achieve optimal health that are experienced by socially disadvantaged populations” (Centers for Disease Control and Prevention, 2008). AYAs with medical conditions from marginalized communities (e.g., people of color, second-language English-speaking, low-income and educational level) and intersecting identities are particularly susceptible to experiencing health disparities in their care (Lotstein et al., 2010).
- **Health equity**, in the context of these guidelines, means “everyone has a fair and just opportunity to be as healthy as possible” (Braveman et al., 2018, p. 2). Reductions in health disparities indicate progress toward health equity. These Professional Practice Guidelines are intended to optimize care and promote health equity for all AYAs with medical conditions.
- **Medical condition** is an acute or chronic disease, disorder, or health problem requiring medical care or surveillance. AYAs with medical conditions may have comorbid developmental, behavioral, and/or mental health disorders; however, these guidelines are not meant to address transitions for AYAs with primary developmental, behavioral, and/or mental health disorders.
- **Medical home** is a centralized source of comprehensive, primary medical care (Jackson et al., 2014). According to the National Survey of Children’s Health (Child and Adolescent Health Measurement Initiative, 2023), having a medical home consists of having a personal doctor or nurse, a usual source for sick care, and family-centered care.
- **Self-efficacy**, in the context of these guidelines, is the belief that one can initiate health behavior change, complete health-related tasks, and achieve health goals (Treadwell et al., 2016).
- **Self-management** may be one of many HCT goals and refers to “the interaction of health behaviors and related processes that patients and families engage in to care for a chronic condition” (p. 474, Modi et al., 2012). This can include skills in managing medications, medical appointments, and health insurance (Sawicki et al., 2011), as well as general self-care skills.
- **Self-Management Transition Enhancement Program (STEP)**
- **Social determinants of health (SDOH)** are environmental conditions that affect a wide range of health, functioning, and quality of life outcomes (Centers for Disease Control and Prevention, 2024) and may contribute to health disparities.
- **Social-Ecological Model of Adolescent and Young Adult Readiness to Transition (SMART)**

- **Social-Ecological Model of Adolescent and Young Adult Readiness to Transition to Promote Health Equity (SMART-E)**
- **Students Helping Individuals Facilitate Transition (SHIFT)**
- **Transfer**, the goal of a transition, is the event that occurs when an individual changes their health care from a pediatric to an adult setting or adult-oriented health care provider (Betz & Telfair, 2007).
- **Transition plan** is a document intended to keep track of all elements of the HCT process. It is co-developed with AYA using information from the transition readiness assessment to guide education and counseling.

References

- Abman, S. H., Bogue, C. W., Baker, S., Carlo, W., Daniels, S. R., Debaun, M. R., Fike, C., Gordon, C. M., Leonard, M. B., Steinhorn, R. H., & Walker-Harding, L. R. (2020). Racism and social injustice as determinants of child health: the American Pediatric Society Issue of the Year. *Pediatric Research*, 88(5), 691–693. <https://doi.org/10.1038/s41390-020-01126-6>
- American Psychological Association. (2024). *APA Task Force on Telepsychology: APA Guidelines for the Practice of Telepsychology (2013, Amended August 2024)*. Retrieved from <https://www.apa.org/about/policy/telepsychology-revisions>
- American Psychological Association. (2023). *Equity, diversity and inclusion: Inclusive language guide (2nd ed.)*. Retrieved from <https://www.apa.org/about/apa/equity-diversity-inclusion/language-guidelines>
- American Psychological Association. (2017). *Multicultural Guidelines: An Ecological Approach to Context, Identity, and Intersectionality*. Retrieved from: <http://www.apa.org/about/policy/multicultural-guidelines.pdf>
- American Psychological Association. (2022). *Psychology's role in advancing population health*. <https://www.apa.org/about/policy/population-health-statement.pdf>
- American Psychological Association. (2025). *Working Group of the Committee on Professional Practice and Standards (COPPS): APA Guidelines for Psychological Practice in Health Care Delivery Systems*. <https://www.apa.org/about/policy/guidelines-health-care-delivery-systems.pdf>
- Americans with Disabilities Act of 1990, 42 U.S.C. § 12101 et. Seq. (1990). <https://www.congress.gov/bill/101st-congress/senate-bill/933>
- Anikputa, B. C., & Horner, S. D. (2023). Perceptions of transitional care needs of adolescents and young adults with special healthcare needs and their parents. *Health Care Transitions*, 1, 100007. <https://doi.org/10.1016/j.hctj.2023.100007>
- Asarnow, J. R., Kolko, D. J., Miranda, J., & Kazak, A. E. (2017). The pediatric patient-centered medical home: Innovative models for improving behavioral health. *The American Psychologist*, 72(1), 13–27. <https://doi.org/10.1037/a0040411>
- Bai, S., Zeledon, L. R., D'Amico, E. J., Shoptaw, S., Avina, C., LaBorde, A. P., Anderson, M., Fitzpatrick, O. M., & Asarnow, J. R. (2018). Reducing health risk behaviors and improving depression in adolescents: A randomized controlled trial in Primary care clinics. *Journal of Pediatric Psychology*, 43(9), 1004–1016. <https://doi.org/10.1093/jpepsy/psy048>
- Barney, A., Mendez-Contreras, S., Hills, N. K., Buckelew, S. M., & Raymond-Flesch, M. (2023). Telemedicine in an adolescent and young adult medicine clinic: A mixed methods study. *BMC Health Services Research*, 23(1), 1–10. <https://doi.org/10.1186/s12913-023-09634-x>
- Baskin, M. L., Collins, M. H., Brown, F., Griffith, J. R., Samuels, D., Moody, A., Thompson, M. P., Eckman, J., & Kaslow, N. J. (1998). Psychosocial considerations in sickle cell disease (SCD): The transition from adolescence to young adulthood. *Journal of Clinical Psychology in Medical Settings*, 5, 315–341. <https://doi.org/10.1023/A:1026206204009>
- Bethell, C. D., Newacheck, P. W., Fine, A., Strickland, B. B., Antonelli, R. C., Wilhelm, C. L., Honberg, L. E., & Wells, N. (2014). Optimizing health and health care systems for children with special health care needs using the life course perspective. *Maternal and Child Health Journal*, 18, 467–477. <https://doi.org/10.1007/s10995-013-1371-1>
- Betz, C. L., Ferris, M. E., Woodward, J. F., Okumura, M. J., Jan, S., & Wood, D. L. (2014). The health care transition research consortium health care transition model: A framework for research and practice. *Journal of Pediatric Rehabilitation Medicine*, 7(1), 3–15. <https://doi.org/10.3233/PRM-140277>
- Betz, C.L. & Telfair, J. (2007) Health care transitions: An introduction. In W. M. Nehring (Ed.), *Promoting health care transitions for adolescents with special health care needs and disabilities* (pp. 3–19). Paul H Brookes Publishing.
- Braveman, P., Arkin, E., Orleans, T., Proctor, D., Acker, J., & Plough, A. (2018). *What is health equity?* *Behavioral Science & Policy*, 4(1), 1–14. [https://doi.org/10.1037/0735-7028.33.6.536](https://doi.org/10.1177/237946151800400102Brown, R. T., Freeman, W. S., Brown, R. A., Belar, C., Hersch, L., Hornyak, L. M., Rickel, A., Rozensky, R., Sheridan, E., & Reed, G. (2002). The role of psychology in health care delivery. <i>Professional Psychology: Research and Practice</i>, 33(6), 536–545. <a href=)
- Byrne, D. G., Davenport, S. C., & Mazanov, J. (2007). Profiles of adolescent stress: The development of the adolescent stress questionnaire (ASQ). *Journal of Adolescence*, 30(3), 393–416. <https://doi.org/10.1016/j.adolescence.2006.04.004>
- Centers for Disease Control and Prevention. (2008). Community Health and Program Services (CHAPS): Health Disparities Among Racial/Ethnic Populations. U.S. Department of Health and Human Services. <https://www.cdc.gov/healthyyouth/disparities/index.htm#1>
- Centers for Disease Control and Prevention. (2024, May 15). *Social Determinants of Health*. U.S. Department of Health and Human Services. <https://www.cdc.gov/public-health-gateway/php/about/social-determinants-of-health.html>
- Child and Adolescent Health Measurement Initiative. (2023, February 10). *2020–2021 National Survey of Children's Health [Data query]*. Data Resource Center for Child and Adolescent Health supported by the U.S. Department of Health and Human Services, Health Resources and Services Administration, & Maternal and Child Health Bureau. www.childhealthdata.org
- Cooley, W. C., Sagerman, P. J., & American Academy of Pediatrics, American Academy of Family Physicians, and American College of Physicians, Transitions Clinical Report Authoring Group. (2011). Supporting the health care transition from adolescence to adulthood in the medical home. *Pediatrics*, 128(1), 182–200. <https://doi.org/10.1542/peds.2011-0969>
- Crosby, L. E., Ware, R. E., Goldstein, A., Walton, A., Joffe, N. E., Vogel, C., & Britto, M. T. (2017). Development and evaluation of iManage: A self-management app co-designed by adolescents with sickle cell disease. *Pediatric Blood & Cancer*, 64(1), 139–145. <https://doi.org/10.1002/pbc.26177>

- Davidson, L. F., Martin, V. S., & Faro, E. Z. (2022). Advancing pediatric primary care practice: Preparing youth for transition from pediatric to adult medical care, a quality improvement initiative. *Journal of Pediatric Nursing*, 66, 171-178. <https://doi.org/10.1016/j.pedn.2022.06.007>
- Devine, K. A., Viola, A., Capucilli, P., Sahler, O. J., & Andolina, J. R. (2017). Factors associated with noncompliance with long-term follow-up care among pediatric cancer survivors. *Journal of Pediatric Hematology/Oncology*, 39(3), 167-173. <https://doi.org/10.1097/MPH.0000000000000744>
- Dunn, D. S., & Andrews, E. E. (2015). Person-first and identity-first language: Developing psychologists' cultural competence using disability language. *American Psychologist*, 70(3), 255-264. <https://doi.org/10.1037/a0038636>
- Ellis, B. J., Bianchi, J., Giskevicius, V., & Frankenhuis, W. E. (2017). Beyond risk and protective factors: An adaptation-based approach to resilience. *Perspectives on Psychological Science*, 12(4), 561-587. <https://doi.org/10.1177/1745691617693054>
- Ellison, J. L., Brown, R. E., & Ameringer, S. (2022). Parents' experiences with health care transition of their adolescents and young adults with medically complex conditions: A scoping review. *Journal of Pediatric Nursing*, 66, 70-78. <https://doi.org/10.1016/j.pedn.2022.04.018>
- Evans, G. W., Li, D., & Whipple, S. S. (2013). Cumulative risk and child development. *Psychological Bulletin*, 139(6), 1342-1396. <https://doi.org/10.1037/a0031808>
- Fredericks, E. M., Magee, J. C., Eder, S. J., Sevecke, J. R., Dore-Stites, D., Shieck, V., & Lopez, M. J. (2015). Quality improvement targeting adherence during the transition from a pediatric to adult liver transplant clinic. *Journal of Clinical Psychology in Medical Settings*, 22(2-3), 150-159. <https://doi.org/10.1007/s10880-015-9427-6>
- Gabriel, P., McManus, M., Rogers, K., & White, P. (2017). Outcome evidence for structured pediatric to adult health care transition interventions: A systematic review. *The Journal of Pediatrics*, 188, 263-269. <https://doi.org/10.1016/j.jpeds.2017.05.066>
- Gray, W. N., Monaghan, M. C., Gilleland Marchak, J., Driscoll, K. A., & Hilliard, M. E. (2015). Psychologists and the transition from pediatrics to adult health care. *The Journal of Adolescent Health*, 57(5), 468-474. <https://doi.org/10.1016/j.jadohealth.2015.07.011>
- Gray, W. N., Schaefer, M. R., Resmini-Rawlinson, A., & Wagoner, S. T. (2018). Barriers to transition from pediatric to adult care: A systematic review. *Journal of Pediatric Psychology*, 43(5), 488-502. <https://doi.org/10.1093/jpepsy/jsx142>
- Gray, W. N., Holbrook, E., Dykes, D., Morgan, P. J., Saeed, S. A., & Denson, L. A. (2019). Improving IBD transition, self-management, and disease outcomes with an in-clinic transition coordinator. *Journal of Pediatric Gastroenterology and Nutrition*, 69(2), 194-199. <https://doi.org/10.1097/MPG.0000000000002350>
- Gray, W. N., Wagoner, S. T., Schaefer, M. R., Reed, B., Morgan, P., Holbrook, E., Yacyshyn, B., Mackner, L., Young, M., Maddux, M., Saeed, S. A., Denson, L. A. & Hommel, K. (2021). Transition to adult IBD care: a pilot multi-site, telehealth hybrid intervention. *Journal of Pediatric Psychology*, 46(1), 1-11. <https://doi.org/10.1093/jpepsy/jsaa088>
- Goddu, A., O'Connor, K. J., Lanzkron, S., Saheed, M. O., Saha, S., Peek, M. E., Haywood, C., Jr., & Beach, M. C. (2018). Do words matter? Stigmatizing language and the transmission of bias in the medical record. *Journal of General Internal Medicine*, 33(5), 685-691. <https://doi.org/10.1007/s11606-017-4289-2>
- Haas, S. A., Schaefer, D. R., & Kornienko, O. (2010). Health and the structure of adolescent social networks. *Journal of Health and Social Behavior*, 51(4), 424-439. <https://doi.org/10.1177/0022146510386791>
- Hamideh, D., & Alvarez, O. (2013). Sickle cell disease related mortality in the United States (1999-2009). *Pediatric Blood & Cancer*, 60(9), 1482-1486. <https://doi.org/10.1002/pbc.24557>
- Hart, L. C., Patel-Nguyen, S. V., Merkley, M. G., & Jonas, D. E. (2019). An evidence map for interventions addressing transition from pediatric to adult care: a systematic review of systematic reviews. *Journal of Pediatric Nursing*, 48, 18-34. <https://doi.org/10.1016/j.pedn.2019.05.015>
- Health Insurance Portability and Accountability Act of 1996, Pub. L. No. 104-191, 100 Stat. 1936 (1996). <https://aspe.hhs.gov/reports/health-insurance-portability-accountability-act-1996>
- Healthy People (2020). *Adolescent health*. U.S. Department of Health and Human Services, Office of Disease Prevention and Health Promotion. <https://wayback.archive-it.org/5774/20220413181755/https://www.healthypeople.gov/2020/topics-objectives/topic/Adolescent-Health>
- Herzer, M., & Hood, K. K. (2010). Anxiety symptoms in adolescents with type 1 diabetes: Association with blood glucose monitoring and glycemic control. *Journal of Pediatric Psychology*, 35(4), 415-425. <https://doi.org/10.1093/jpepsy/jsp063>
- Holland, J. E., Rettew, D. C., Varni, S. E., & Harder, V. S. (2023). Associations between mental and physical illness comorbidity and hospital utilization. *Hospital Pediatrics*, 13(9), 841-848. <https://doi.org/10.1542/hpeds.2022-006984>
- Holmbeck, G. N., & Devine, K. A. (2010). Psychosocial and family functioning in spina bifida. *Developmental Disabilities Research Reviews*, 16(1), 40-46. <https://doi.org/10.1002/ddrr.90>
- Hood, K. K., Rausch, J. R., & Dolan, L. M. (2011). Depressive symptoms predict change in glycemic control in adolescents with type 1 diabetes: Rates, magnitude, and moderators of change. *Pediatric Diabetes*, 12(8), 718-723. <https://doi.org/10.1111/j.1399-5448.2011.00771.x>
- Idalski Carcone, A., Ellis, D. A., Weisz, A., & Naar-King, S. (2011). Social support for diabetes illness management: Supporting adolescents and caregivers. *Journal of Developmental and Behavioral Pediatrics*, 32(8), 581-590. <https://doi.org/10.1097/DBP.0b013e31822c1a27>
- Jackson, G. L., Powers, B. J., Chatterjee, R., Prvu Bettger, J., Kemper, A. R., Hasselblad, V., Dolor, R. J., Irvine, R. J., Heidenfelder, B. L., Kendrick, A. S., Gray, R., & Williams Jr, J. W. (2013). The patient-centered medical home: A systematic review. *Annals of Internal Medicine*, 158(3), 169-178. <https://doi.org/10.7326/0003-4819-158-3-201302050-00579>

- Karyotaki, E., Cuijpers, P., Albor, Y., Alonso, J., Auerbach, R. P., Bantjes, J., Bruffaerts, R., Ebert, D. D., Hasking, P., Kiekens, G., Lee, S., McLafferty, M., Mak, A., Mortier, P., Sampson, N. A., Stein, D. J., Vilagut, G., & Kessler, R. C. (2020). Sources of stress and their associations with mental disorders among college students: Results of the World Health Organization World Mental Health Surveys International College Student Initiative. *Frontiers in Psychology, 11*, 1759. <https://doi.org/10.3389/fpsyg.2020.01759>
- King-Dowling, S., Psihogios, A. M., Hill-Kayser, C., Szalda, D., O'Hagan, B., Darabos, K., Daniel, L. C., Barakat, L. P., Fleisher, L., Maurer, L. A., Velázquez-Martin, B., Jacobs, L. A., Hobbie, W., Ginsberg, J. P., Vachani, C. C., Metz, J. M., & Schwartz, L. A. (2021). Acceptability and feasibility of survivorship care plans and an accompanying mobile health intervention for adolescent and young adult survivors of childhood cancer. *Pediatric Blood & Cancer, 68*(3), e28884. <https://doi.org/10.1002/pbc.28884>
- Kirk, S., Beatty, S., Callery, P., Milnes, L., & Prymachuk, S. (2012). Perceptions of effective self-care support for children and young people with long-term conditions. *Journal of Clinical Nursing, 21*(13-14), 1974-1987. <https://doi.org/10.1111/j.1365-2702.2011.04027.x>
- Kolko, D. J., Campo, J., Kilbourne, A. M., Hart, J., Sakolsky, D., & Wisniewski, S. (2014). Collaborative care outcomes for pediatric behavioral health problems: A cluster randomized trial. *Pediatrics, 133*(4), e981-e992. <https://doi.org/10.1542/peds.2013-2516>
- La Greca, A. M., & Mackey, E. R. (2009). Type 1 diabetes mellitus. In W. T. O'Donohue & L. W. Tolle (Eds.), *Behavioral approaches to chronic disease in adolescence: A guide to integrative care* (pp. 85-100). Springer. https://doi.org/10.1007/978-0-387-87687-0_8
- Leeb, R. T., Danielson, M. L., Bitsko, R. H., Cree, R. A., Godfred-Cato, S., Hughes, M. M., ... & Lebrun-Harris, L. A. (2020). Support for transition from adolescent to adult health care among adolescents with and without mental, behavioral, and developmental disorders—United States, 2016-2017. *Morbidity and Mortality Weekly Report, 69*(34), 1156-1160. <https://doi.org/10.15585/mmwr.mm6934a2>
- Levy, B. B., Song, J. Z., Luong, D., Perrier, L., Bayley, M. T., Andrew, G., Arbour-Nicitopoulos, K., Chan, B., Curran, C. J., Dimitropoulos, G., Hartman, L., Huang, L., Kastner, M., Kingsnorth, S., McCormick, A., Nelson, M., Nicholas, D., Penner, M., Thomson, L., Toulany, A., ... & Munce, S. E. (2020). Transitional care interventions for youth with disabilities: A systematic review. *Pediatrics, 146*(5). <https://doi.org/10.1542/peds.2020-0187>
- Lindsay, S., Kingsnorth, S., Mcdougall, C., & Keating, H. (2014). A systematic review of self-management interventions for children and youth with physical disabilities. *Disability and Rehabilitation, 36*(4), 276-288. <https://doi.org/10.3109/09638288.2013.785605>
- Lotstein, D. S., Kuo, A. A., Strickland, B., & Tait, F. (2010). The transition to adult health care for youth with special health care needs: Do racial and ethnic disparities exist? *Pediatrics, 126*(Supplement_3), S129-S136. <https://doi.org/10.1542/peds.2010-1466F>
- Mattson, G., Kuo, D. Z., Committee on Psychosocial Aspects of Child and Family Health, & Council on Children with Disabilities (2019). Psychosocial factors in children and youth with special health care needs and their families. *Pediatrics, 143*(1), e20183171. <https://doi.org/10.1542/peds.2018-3171>
- McKenzie, R. B., Sanders, L., Bhattacharya, J., & Bundorf, M. K. (2019). Health care system factors associated with transition preparation in youth with special health care needs. *Population Health Management, 22*(1), 63-73. <https://doi.org/10.1089/pop.2018.0027>
- McManus, M., White, P., & Schmidt, A. (2018). Recommendations for value-based transition payment for pediatric and adult health care systems: A leadership roundtable report. Washington, DC: The National Alliance to Advance Adolescent Health.
- McPheeters, M., Davis, A. M., Taylor, J. L., Brown, R. F., Potter, S. A., & Epstein, R. A. (2014). *Transition care for children with special health needs*. (Publication No.14-EHC027-EF). Agency for Healthcare Research and Quality. <https://pubmed.ncbi.nlm.nih.gov/25057736/>
- Modi, A. C., Pai, A. L., Hommel, K. A., Hood, K. K., Cortina, S., Hilliard, M. E., Guilfoyle, S. M., Gray, W. N., & Drotar, D. (2012). Pediatric self-management: a framework for research, practice, and policy. *Pediatrics, 129*(2), e473-e485. <https://doi.org/10.1542/peds.2011-1635>
- Monaghan, M., Hilliard, M., Sweeney, R., & Riekert, K. (2013). Transition readiness in adolescents and emerging adults with diabetes: the role of patient-provider communication. *Current Diabetes Reports, 13*(6), 900-908. <https://doi.org/10.1007/s11892-013-0420-x>
- Mulye, T. P., Park, M. J., Nelson, C. D., Adams, S. H., Irwin, C. E., Jr, & Brindis, C. D. (2009). Trends in adolescent and young adult health in the United States. *The Journal of Adolescent Health, 45*(1), 8-24. <https://doi.org/10.1016/j.jadohealth.2009.03.013>
- The National Alliance to Advance Adolescent Health. (n.d.). *Got Transition® Six Core Elements of Health Care Transition™*. Retrieved January 11, 2024, from <https://www.gottransition.org/six-core-elements/>
- National Institute of Mental Health (2023, March). Mental Illness. Retrieved from <https://www.nimh.nih.gov/health/statistics/mental-illness>
- Nibras, S., Kentor, R., Masood, Y., Price, K., Schneider, N. M., Tenenbaum, R. B., & Calarge, C. (2022). Psychological and psychiatric comorbidities in youth with serious physical illness. *Children (Basel, Switzerland), 9*(7), 1051. <https://doi.org/10.3390/children9071051>
- O'Reilly, Meag-gan (2020, June 5). Systems centered language. *Medium*. <https://meagoreillyphd.medium.com/systems-centered-language-a3dc7951570e>
- Oswald, D. P., Gilles, D. L., Cannady, M. S., Wenzel, D. B., Willis, J. H., & Bodurtha, J. N. (2013). Youth with special health care needs: Transition to adult health care services. *Maternal and Child Health Journal, 17*(10), 1744-1752. <https://doi.org/10.1007/s10995-012-1192-7>
- Pai, A. L., & Ostendorf, H. M. (2011). Treatment adherence in adolescents and young adults affected by chronic illness during the health care transition from pediatric to adult health care: A literature review. *Children's Health Care, 40*(1), 16-33. <https://doi.org/10.1080/02739615.2011.537934>

- Palermo, T. M., Janicke, D. M., McQuaid, E. L., Mullins, L. L., Robins, P. M., & Wu, Y. P. (2014). Recommendations for training in pediatric psychology: Defining core competencies across training levels. *Journal of Pediatric Psychology*, 39(9), 965–984. <https://doi.org/10.1093/jpepsy/jsu015>
- Parfeniuk, S., Petrovic, K., MacIsaac, P. L., Cook, K. A., & Rempel, G. R. (2020). Transition readiness measures for adolescents and young adults with chronic health conditions: A systematic review. *Journal of Transition Medicine*, 2(1), 20200020. <https://doi.org/10.1515/jtm-2020-0020>
- Prior, M., McManus, M., White, P., & Davidson, L. (2014). Measuring the “triple aim” in transition care: a systematic review. *Pediatrics*, 134(6), e1648–e1661. <https://doi.org/10.1542/peds.2014-1704>
- Prussien, K. V., Crosby, L. E., Faust, H. L., Barakat, L. P., Deatrick, J. A., Smith-Whitley, K., & Schwartz, L. A. (2024). An updated equitable model of readiness for transition to adult care: Content validation in young people with sickle cell disease. *JAMA Pediatrics*, 178(3), 274–282. <https://doi.org/10.1001/jamapediatrics.2023.5914>
- Rachas, A., Lefevre, D., Meyer, L., Faye, A., Mahlaoui, N., de La Rochebrochard, E., Warszawski, J., & Durieux, P. (2016). Evaluating continuity during transfer to adult care: A systematic review. *Pediatrics*, 138(1). <https://doi.org/10.1542/peds.2016-0256>
- Rapp, A. M., Chavira, D. A., Sugar, C. A., & Asarnow, J. R. (2017). Integrated primary medical-behavioral health care for adolescent and young adult depression: Predictors of service use in the youth partners in care trial. *Journal of Pediatric Psychology*, 42(9), 1051–1064. <https://doi.org/10.1093/jpepsy/jsx057>
- Reed-Knight, B., Blount, R. L., & Gilleland, J. (2014). The transition of health care responsibility from parents to youth diagnosed with chronic illness: A developmental systems perspective. *Families, Systems, & Health*, 32(2), 219–234. <https://doi.org/10.1037/fsh0000039>
- Roberts, G., Vazquez-Ortiz, M., Knibb, R., Khaleva, E., Alviani, C., Angier, E., Blumchen, K., Comberiati, P., Duca, B., DunnGalvin, A., Garriga-Baraut, T., Gore, C., Gowland, M. H., Hox, V., Jensen, B., Mortz, C. G., Pfaar, O., Pite, H., Santos, A. F., ... & Timmermans, F. (2020). EAACI Guidelines on the effective transition of adolescents and young adults with allergy and asthma. *Allergy*, 75(11), 2734–2752. <https://doi.org/10.1111/all.14459>
- Rodriguez, E., Tonn, T., Jafry, M., Xiao, Q., Cuglievan, B., Ahmed, S., Livingston, J. A. A., Aune, G. J., Albritton, K. H., Flowers, C., Roth, M., & Hildebrandt, M. A. T. (2023). Social determinants of health burden among adolescent and young adult cancer patients and impact on overall survival. *Journal of Clinical Oncology*, 41(16_supplement) 12017. https://doi.org/10.1200/JCO.2023.41.16_suppl.12017
- Rosenberg-Yunger, Z. R., Klassen, A. F., Amin, L., Granek, L., D'Agostino, N. M., Boydell, K. M., Greenberg M., Barr R. D., & Nathan, P. C. (2013). Barriers and facilitators of transition from pediatric to adult long-term follow-up care in childhood cancer survivors. *Journal of Adolescent and Young Adult Oncology*, 2(3), 104–111. <https://doi.org/10.1089/jayao.2013.0003>
- Roy, K., Kamath, V., & Kamath, A. (2015). Determinants of adolescent stress: A narrative review. *European Journal of Psychology & Educational Studies*, 2(2), 48–56. https://www.researchgate.net/publication/285383246_Determinants_of_adolescent_stress_A_narrative_review
- Sawicki, G. S., Kelemen, S., & Weitzman, E. R. (2014). Ready, set, stop: Mismatch between self-care beliefs, transition readiness skills, and transition planning among adolescents, young adults, and parents. *Clinical Pediatrics*, 53(11), 1062–1068. <https://doi.org/10.1177/0009922814541169>
- Sawicki, G. S., Lukens-Bull, K., Yin, X., Demars, N., Huang, I. C., Livingood, W., Reiss, J., & Wood, D. (2011). Measuring the transition readiness of youth with special healthcare needs: Validation of the TRAQ—Transition Readiness Assessment Questionnaire. *Journal of Pediatric Psychology*, 36(2), 160–171. <https://doi.org/10.1093/jpepsy/jsp128>
- Scal, P., & Ireland, M. (2005). Addressing transition to adult health care for adolescents with special health care needs. *Pediatrics*, 115(6), 1607–1612. <https://doi.org/10.1542/peds.2004-0458>
- Schmidt, A., Ilango, S. M., McManus, M. A., Rogers, K. K., & White, P. H. (2020). Outcomes of pediatric to adult health care transition interventions: an updated systematic review. *Journal of Pediatric Nursing*, 51, 92–107. <https://doi.org/10.1016/j.pedn.2020.01.002>
- Schwartz, L. A., Brumley, L. D., Tuchman, L. K., Barakat, L. P., Hobbie, W. L., Ginsberg, J. P., ... & Deatrick, J. A. (2013). Stakeholder validation of a model of readiness for transition to adult care. *JAMA Pediatrics*, 167(10), 939–946. <https://doi.org/10.1001/jamapediatrics.2013.2223>
- Schwartz, L. A., Daniel, L. C., Brumley, L. D., Barakat, L. P., Wesley, K. M., & Tuchman, L. K. (2014). Measures of readiness to transition to adult health care for youth with chronic physical health conditions: A systematic review and recommendations for measurement testing and development. *Journal of Pediatric Psychology*, 39(6), 588–601. <https://doi.org/10.1093/jpepsy/jsu028>
- Schwartz, L. A., Tuchman, L. K., Hobbie, W. L., & Ginsberg, J. P. (2011). A social-ecological model of readiness for transition to adult-oriented care for adolescents and young adults with chronic health conditions. *Child: Care, Health and Development*, 37(6), 883–895. <https://doi.org/10.1111/j.1365-2214.2011.01282.x>
- Sharma, N., O'Hare, K., O'Connor, K.G., Nehal, U., & Okumura, M.J. (2018). Care coordination and comprehensive electronic health records are associated with increased transition planning activities. *Academic Pediatrics*, 18(1), 111–118. <https://doi.org/10.1016/j.acap.2017.04.005>
- Shonkoff, J. P., Garner, A. S., Siegel, B. S., Dobbins, M. I., Earls, M. F., McGuinn, L., Pascoe, J., & Wood, D. L. (2012). The lifelong effects of early childhood adversity and toxic stress. *Pediatrics*, 129(1), e232–e246. <https://doi.org/10.1542/peds.2011-2663>
- Sun, M., Oliwa, T., Peek, M. E., & Tung, E. L. (2022). Negative patient descriptors: Documenting racial bias in the electronic health record: Study examines racial bias in the patient descriptors used in the electronic health record. *Health Affairs*, 41(2) 203–211. <https://doi.org/10.1377/hlthaff.2021.01423>

- Suris, J. C., Michaud, P. A., & Viner, R. (2004). The adolescent with a chronic condition. Part I: Developmental issues. *Archives of Disease in Childhood*, 89(10), 938–942. <https://doi.org/10.1136/adc.2003.045369>
- Syed, S., Wroblewski, K., Peddinti, R., Lapping-Carr, G., & Darlington, W. S. (2021). Food insecurity, quality of life, healthcare utilization, and clinical disease outcomes in AYA patients with sickle cell disease. *Blood*, 138(Supplement 1), 972. <https://doi.org/10.1182/blood-2021-148171>
- Szalda, D., Piece, L., Brumley, L., Li, Y., Schapira, M. M., Wasik, M., Hobbie, W. L., Ginsberg, J. P., & Schwartz, L. A. (2017). Associates of engagement in adult-oriented follow-up care for childhood cancer survivors. *The Journal of Adolescent Health*, 60(2), 147–153. <https://doi.org/10.1016/j.jadohealth.2016.08.018>
- Tebb, K. P., Pica, G., Twietmeyer, L., Diaz, A., & Brindis, C. D. (2018). Innovative approaches to address social determinants of health among adolescents and young adults. *Health Equity*, 2(1), 321–328. <https://doi.org/10.1089/heq.2018.0011>
- Treadwell, M., Johnson, S., Sisler, I., Bitsko, M., Gildengorin, G., Medina, R., Barreda, F., Major, K., Telfair, J., & Smith, W. R. (2016). Self-efficacy and readiness for transition from pediatric to adult care in sickle cell disease. *International Journal of Adolescent Medicine and Health*, 28(4), 381–388. <https://doi.org/10.1515/ijamh-2015-0014>
- Trent, M., Dooley, D. G., Dougé, J., Cavanaugh, R. M., Lacroix, A. E., Fanburg, J., Rahmandar, M. H., Hornberger, L. L., Scheider, M. B., Yen, S., Chilton, L. A., Green, A. E., Dilley, K. J., Gutierrez, J. R., Duffee, J. H., Keanne, V. A., Krugman, S. D., McKelvy, C. D., Linton, J. M., ... & Wallace, S. B. (2019). The impact of racism on child and adolescent health. *Pediatrics*, 144(2), e20191765. <https://doi.org/10.1542/peds.2019-1765>
- Tsang, V. W., Fletcher, S., Jassemi, S., & Smith, S. (2022). Youth, caregiver, and provider perception of the transition from pediatric to adult care for youth with chronic diseases. *Journal of Developmental & Behavioral Pediatrics*, 43(4), 197–205. <https://doi.org/10.1097/DBP.0000000000001024>
- United States Census Bureau (2014). 2010–2014 ACS 5-Year Data Profile [Dataset]. <https://www.census.gov/acs/www/data/data-tables-and-tools/data-profiles/2014/>
- van Staa, A., van der Stege, H. A., Jedeloo, S., Moll, H. A., & Hilberink, S. R. (2011). Readiness to transfer to adult care of adolescents with chronic conditions: exploration of associated factors. *Journal of Adolescent Health*, 48(3), 295–302. <https://doi.org/10.1016/j.jadohealth.2010.07.009>
- Viner, R. M., Ozer, E. M., Denny, S., Marmot, M., Resnick, M., Fatusi, A., & Currie, C. (2012). Adolescence and the social determinants of health. *The Lancet*, 379(9826), 1641–1652. [https://doi.org/10.1016/S0140-6736\(12\)60149-4](https://doi.org/10.1016/S0140-6736(12)60149-4)
- Viola, A. S., Drachtman, R., Kaveney, A., Sridharan, A., Savage, B., Delnevo, C. D., Coups, E. J., Porter, J. S., & Devine, K. A. (2021). Feasibility of medical student mentors to improve transition in sickle cell disease. *Journal of Pediatric Psychology*, 46(6), 650–661. <https://doi.org/10.1093/jpepsy/jsab031>
- Wang, G., McGrath, B. B., & Watts, C. (2010). Health care transitions among youth with disabilities or special health care needs: An ecological approach. *Journal of Pediatric Nursing*, 25(6), 505–550. <https://doi.org/10.1016/j.pedn.2009.07.003>
- White, P. H., Cooley, W. C., Boudreau, A. D. A., Cyr, M., Davis, B. E., Dreyfus, D. E., ... & American Academy of Family Physicians. (2018). Supporting the health care transition from adolescence to adulthood in the medical home. *Pediatrics*, 142(5). <https://doi.org/10.1542/peds.2018-2587>
- White, P., Schmidt, A., Shorr, J., Ilango, S., Beck, D., McManus, M. (2020). *Six Core Elements of Health Care Transition™ 3.0. Got Transition, The National Alliance to Advance Adolescent Health*. Retrieved August 5, 2024, from <https://www.gottransition.org/6ce/?leaving-full-package>
- Wisk, L. E., Finkelstein, J. A., Sawicki, G. S., Lakoma, M., Toomey, S. L., Schuster, M. A., & Galbraith, A. A. (2015). Predictors of timing of transfer from pediatric- to adult-focused primary care. *JAMA Pediatrics*, 169(6), e150951. <https://doi.org/10.1001/jamapediatrics.2015.0951>
- World Health Organization. (2024, November). Adolescent and Young Adult Health. <https://www.who.int/news-room/fact-sheets/detail/adolescents-health-risks-and-solutions>



AMERICAN
PSYCHOLOGICAL
ASSOCIATION