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Position paper

Transition to Adulthood for Youth With Chronic Conditions and Special Health Care Needs

Society for Adolescent Health and Medicine



A B S T R A C T

In 2003, the Society for Adolescent Medicine issued a position paper joining the American Academy of Pediatrics, the American Academy of Family Physicians, and the American College of Physicians in endorsing a national consensus statement regarding successful transition to adult care, for all young people, including youth with special health care needs. This consensus statement was followed by a clinical report in 2011, which was updated in 2018. Since the original publication, the development of professional guidelines, several iterations of U.S.-based national survey data, and a growing global evidence base characterizing the consequences of suboptimal transitions have advanced the field of health care transition substantially. Barriers to and facilitators of successful transition have been described along with a number of social-, economic-, and health care systems-level issues that require coordinated professional advocacy. The goal of this revised position paper is to review the interim developments in health care transition for youth with special health care needs and refine Society of Adolescent Health and Medicine's position to align with the most recent evidence and professional consensus, including the incorporation of insights and recommendations from the latest revised clinical report.

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Positions of the Society of Adolescent Health and Medicine

Based on the review of the most recent literature and guidelines, Society of Adolescent Health and Medicine (SAHM) endorses:

1. Youth with special health care needs (YSHCN) and their families need educational, psychosocial, and medical support from their health care teams during the transition from pediatric to adult health care, including special attention to the social determinants of health.
2. Pediatric and adult providers and trainees should receive education and organizational support from health care systems to care for YSHCN in a comprehensive and developmentally appropriate manner.
3. Care services and transition processes should be formally evaluated and monitored with reproducible measures whenever possible, and research should focus on the validity of these measures as well as identification of reliable outcomes.
4. Technology such as electronic health records (EHRs) and telehealth tools should continue to be developed to extend and strengthen the transition continuum of care.

5. Financial funding models and access for health care transition (HCR) should support practices that lead to optimal longitudinal health outcomes for YSHCN, regardless of age, insurance status, or level of disability.

Important Definitions

HCT: the process of moving from a pediatric to an adult model of health care with or without a *transfer* to a new health care provider [1].

YSHCN: have or are at increased risk for chronic physical, developmental, behavioral, or emotional conditions and also require health and related services of a type or amount beyond that required by youth generally.

Statement of the Problem

YSHCN are living well into adulthood [2]. Without a planned and coordinated transition to adult care, decreased adherence to essential treatments and difficulties in accessing needed services may lead to poor health outcomes [3–5].

YSHCN use a disproportionate share of resources in children's hospitals [6], challenging the ability of health systems to care for this population effectively. As the young adult population continues to grow and diversify, the many complex social determinants of health that affect the transition process must be accounted for. Guidelines, frameworks, and consensus papers need to be customizable to local circumstances and the cultural and socioeconomic composition of patients and their families.

In 2002, several medical professional societies issued a policy statement [7] (subsequently endorsed by SAM [8]) calling for the provision of high-quality, compassionate, developmentally appropriate, and continuous medical care for YSHCN. Such care is multifaceted and ranges from finding appropriate adult providers well equipped to handle the changing health care needs of young adults to the maintenance of adequate insurance coverage throughout this period. The main source of health care support is often a primary care provider or a patient-centered medical home that works with a multidisciplinary team of allied health professionals, including social workers, advanced practice providers, community health workers, and health care system navigators [9]. In these settings, it is expected that health care systems support the transition process through clinical decision tools in the EHR and portable medical summaries and transition plans, as discussed further below. It is also understood that the sequencing of transitioning specialty care may vary from individual to individual, as not all pediatric specialties have equivalent adult counterparts, and some may necessitate transfer before or after that of their primary care.

Although the field of HCT has evolved since the joint policy statement was originally formulated nearly two decades ago, patients, families, and providers continue to experience challenges to seamless and effective transition worldwide [10], underscoring the need for a more coordinated and better-resourced transition and transfer process [11]. In recent years, more sophisticated professional guidelines have been issued, including the most recent 2018 Clinical Report *Supporting the Health Care Transition from Adolescence to Adulthood in the Medical Home* [1], which outlines concrete expert recommendations for clinical infrastructure, education/training, payment models, and research. This report also helps catalog proposed core outcomes in attempts to formalize and evaluate efforts to transition YSHCN to adult care in a safe and timely manner. Similarly, the Transition Research Programme from the United Kingdom released a patient-, family- and provider-derived set of initiatives in 2019 that encourages a health system-wide approach to developmentally appropriate care, with efforts shared across the pediatric and adult care continuum [10]. This particular Programme also calls for parental involvement, namely in fostering confidence in one's health care decision-making, when appropriate, in the transition process, all of which can be broadly applicable worldwide [10].

Methods

This position paper was developed by reviewing the current scientific literature on HCT with special attention to YSHCN, as well as professional consensus among a team of leaders and experts in the field of HCT.

Positions and Recommendations

Position 1: YSHCN and their families need educational, psychosocial, and medical support from their health care teams during the transition from pediatric to adult health care, including special attention to the social determinants of health

Adolescents and young adults, especially those with SHCN, are a vulnerable population. Certain nondominant groups within this cohort are even more marginalized, including those emerging from the Foster Care system, Juvenile Justice system, and racial, ethnic, and socioeconomic minorities. These groups are less likely to experience a successful transition to adulthood [12]. Current literature recommends considering socioecological models of HCT, and SAHM embraces this approach as well [13]. Even for those without SHCN, young people (and their providers) can benefit from skills and knowledge surrounding transition, as many AYA reengage in the health care system only with an inciting event (i.e., illness, injury, pregnancy, etc.) that may force or potentially compromise a safe HCT.

In addition, those patients with developmental disabilities require a nuanced approach to HCT, often warranting neuropsychiatric evaluations that require specially trained providers. It is important that research continue to explore simpler ways to have these individuals undergo the neuropsychiatric testing necessary to secure adequate support and resources during the transition period and beyond. These individuals also often require decision-making support, which adult providers need to be made aware of in transfer summaries, so that providers can help guide patients to the appropriate legal resources to obtain the necessary support.

Position 2: Pediatric and adult providers and trainees should receive education and organizational support from health care systems to care for YSHCN in a comprehensive and developmentally appropriate manner

To optimally support the HCT process, health care providers need to receive adequate education and guidance on how to ensure safe and timely transition. Studies show that both pediatric and adult providers feel inadequately prepared for this process [1]. Medical students and residents should be educated about how to transition YSHCN. Providers focused on adult health care should be familiar with pediatric conditions that are becoming more common in adult medicine such as various congenital conditions (i.e., congenital heart disease, spina bifida, and neurodevelopmental delays). Both SAHM and the AAP have offered online modules for this purpose in recent years [14,15]. Several professional organizations have recently joined forces to ensure the development and dissemination of resources for their respective fields. For example, the Transition Committee of the Med-Peds Program Directors Association recently published an HCT curriculum for primary care residents [16]. The ACP has published a toolkit consisting of provider resources ranging from pre- and post-transfer self-assessments for patients to clinical summary/transfer templates for providers [17]. The materials are designed for primary care and specialty providers to maximally support the patient's entire care team in the transition process. The Society of General Internal Medicine recently published a comprehensive textbook to guide adult providers through the transition process for patients with common childhood-onset

chronic conditions [18]. In addition, the Maternal and Child Health Bureau provided a number of proposed transition plans and processes that can be tailored to various models involving pediatric, adult, and family medicine practices [19]. We support the utilization of these resources to help guide the implementation of HCT practices in various health care settings.

Position 3: Care services and transition processes should be formally evaluated and monitored with reproducible measures whenever possible, and research should focus on the validity of these measures as well as identification of reliable outcomes

Supporting HCT through an organized, reproducible, and measurable process is important and has been increasingly studied in recent years. Identifying and tracking YSHCN as they move through the transition process can help ensure that plans are developed, and needs are met in a way that is appropriate and useful for the patient, family, and care team. Processes and outcomes related to transition should be the focus of research going forward. This research should include the development of valid measures as well as quality improvement and implementation/dissemination approaches. Research should also help identify health service needs on a local and population health level. One example of this is the *Six Core Elements of Health Care Transition* [18], a process proposed by the Maternal and Child Health Bureau and Center for Health Care Transition Improvement (*GotTransition*) in response to the joint professional consensus guidelines issued by the ACP, AAFP, and AAP in 2011 [9]. The *Six Core Elements* outline a systematic and population health–based approach to HCT that has been applied to primary care and subspecialty clinical practices. Resources are available to aid organizations in drafting transition policies and practices that help guide patients and families throughout the entire transition process. It can also serve as a quality improvement platform to iteratively evaluate transition programs [20]. Using this or a similar model can help individual care teams or health systems align their transition practices with the “triple aim” of healthcare—addressing population health needs, patient experience, and cost [21]. The fidelity to processes such as *The Six Core Elements* should be further examined to identify barriers to implementation across varying health systems worldwide.

Position 4: Technology such as EHRs and telehealth tools should continue to be developed to extend and strengthen the transition continuum of care

The medical field is advancing technologically, with the routine implementation of EHR and virtual care platforms. Incorporation of planning tools including patient registries as well as point-of-care knowledge and transition assessments and support materials for patients and families have been shown to be feasible and well received by primary care and subspecialty providers [22]. Another imperative component of a smooth and safe transition is ensuring the organization and transmission of high-quality information between the health care team and patients and families as well as between providers. In addition to care coordination services, comprehensive EHR can aid in the development and dissemination of a coordinated transition plan [23]. Platforms such as *Good two Go*, a data-sharing and medical passport program in Toronto, Canada, is an example of how such

electronic interfaces can potentiate smooth and safe transitions [24]. Implementation of mobile health (“mHealth”) tools to maximize adherence and patient engagement are also promising in optimizing transitions to adult care for YSHCN [25]. Finally, the exploration and implementation of telehealth platforms appear to be playing an increasingly important role in information sharing, health care accessibility, and patient and provider comfort in transition to adult care [26].

Position 5: Financial models and access for HCT should support practices that lead to optimal longitudinal health outcomes for YSHCN, regardless of age, insurance status, or level of disability

In addition to the clinical, educational, and organizational supports discussed previously, the transition process requires financial funding models that support essential care coordination [1]. Globally and also within each country, there are diverse health financing systems that differ across the source of funds, payment of services, risk/costs burden, and level of coverage. Provider payment models range from fee-for-service (FFS) to capitation, diagnosis-related groups, pay-for-performance, and salary. These result in different incentives, which influence the quantity and quality of the health care delivered, for example, FFS rewards the provision of direct clinical interventions. Transition care coordination may not be delivered face-to-face and is more readily funded under fixed payment approaches such as capitated payments or pay-for-performance models that incentivize population health management and are directed to outcomes. Integrated delivery systems and reimbursement bonuses for patient-centered medical home–designated clinics may be another way to fund and enhance the structural processes for transition support. These models offer health care systems the opportunity to invest in transition as a preventative approach for anticipated short- and long-term cost savings from improved general health and optimal chronic disease management and may help support cases of “shared-care” (between pediatric and adult providers) for individuals who cannot fully transition to adult care. Furthermore, for those regions of the world using a public (vs. private) health insurance system (i.e., Medicaid in the U.S.), it is important that any associated Managed Care Organizations be fully informed of and contracted to comprehensively support the costs associated with HCT. We support the move away from FFS payment models and to health funding mechanisms that support transition coordination of care and preventative interventions for longitudinal investment in the health of this vulnerable population.

Summary

Successful and effective HCTs are possible for all youth, including those with special health care needs but require support at the family, medical home, and health system levels. Provider education, multidisciplinary team-based support, and technological innovations are all components of building a system to support youth as they move into adult health care.

Opportunities to improve the transition of YSHCN to adult health care continue to increase worldwide as financial funding models evolve toward outcome-based care, which supports care coordination. This position statement affirms the need for ongoing research and health care services support to ensure successful HCTs for all youth.

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