Chapter 1
Development of Healthcare Transition Policy and Concepts

Cecily L. Betz

Introduction

The evolution of the field of healthcare transition (HCT) emanated in part from the increasing numbers of adolescents with childhood-acquired disabilities and chronic conditions who entered into adulthood. Ninety percent of children born with chronic conditions are now projected to survive into adulthood [58]. According to recent estimates, approximately one million adolescents with chronic conditions reach adulthood and enter the adult system of health care [47]. Of the number of adolescents entering the adult healthcare system, approximately 3% are identified as having complex medical needs, referred to in pediatric care as children with medical complexity (CMC). This subgroup of adolescents with complex medical needs are so described as they have significant functional limitations (i.e., technology dependent; non-ambulatory); have extensive needs for a myriad of specialty medical services; and have disproportionate health utilization compared to typical usage of health care services as they are at higher risk for hospitalization and emergency department visits [1, 17, 35, 36].

The evident, yet unexpected, surge of this new population of adolescents and young adults with complex healthcare needs has created new challenges for both pediatric and adult healthcare systems. These ever growing and pressing developments have been exacerbated by the inadequacy of service models for facilitating the exit from pediatric care and the access to adult care as no formal transfer linkages between them has existed. Problematic as well has been the lack of preparation programs to support adolescents and young adults and their families for the transition from pediatric to adult health care. Findings of the 2016 National Survey of

C. L. Betz (✉)
Keck School of Medicine, Department of Pediatrics, University of Southern California, Los Angeles, CA, USA
e-mail: cbetz@chla.usc.edu

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Children's Health (NSCH) revealed the vast majority of adolescents with (83%) and without (86%) special healthcare needs (SHCN) had not received HCT preparation according to national performance metrics [38]. Furthermore, providers in both sectors of this system of health care have been ill equipped to provide the services needed for preparing this new population of medically complex patients to leave pediatric care and to access the care of healthcare professionals positioned to receive them [53].

The intent of this chapter is to provide the reader with a historical perspective about the early roots and beginnings of the field of HCT practice and research. To accomplish this purpose, the narrative will begin with the causative factors that created the needs for this new model of service for young adults and adults with childhood-acquired long-term conditions. These factors created the recognition of the need for change as well as the challenges in effecting the development and implementation of HCT service models. In essence, a massive reshaping of the exit portal of the pediatric system of care together with a conduit of entrance into adult care was needed as historical policy-related precedents were formidable opposing factors to effect change. The professional and governmental developments that ensued during the seminal stages of the field will be presented, ending with a "snapshot" of current developments in research and practice and the implications for the future.

Survival Rates of Children with Long-Term Conditions: Then and Now

The advances in the science and care of children born with congenital disorders and those diagnosed with long-term conditions within the last generation alone have brought remarkable changes in the treatment and long-term management of this vulnerable pediatric population. The dramatic contrasts in survivability as described here are illustrative. In the late 1930s, more than 70% of children diagnosed with cystic fibrosis (CF) died before the age of 2 years. Today, life expectancy for individuals born with CF extends into the mid and late 40s [18, 19, 21, 66]. In 1970, less than 50% of adolescents diagnosed with sickle cell disease survived into adulthood [64]. Recent reports indicate that 93.9% of with sickle cell anemia (HbSS) or sickle 0-thalassemia (HbSβ°) survive into adulthood with a medium age of survival over 50. Nearly all (98.4%) of those with sickle hemoglobin C disease (HbSC) or sickle thalassemia (HbSβ^{+}) have survival rates comparable to the typical population [14, 15, 59].

Prior to the neurosurgical treatment of infants born with spina bifida (SB), most often it was considered as a fatal diagnosis [37]. The survival rates of infants born with SB in the 1960s and 1970s improved with more aggressive treatment approaches enabling more favorable prognosis beyond infancy and childhood [28, 41, 46, 54]. Adulthood survival rate estimates, although dependent on the level of SB involvement, are now reported as 60% for survival into the 20s [60]. More recent studies

have reported survival rates of 39% for age 40 and 32% for age 50 that are based on longitudinal study of cohort of children born (between 1963 and 1971) in the United Kingdom [54, 55].

In the 1960s, for children diagnosed with Duchenne muscular dystrophy (DMD), life expectancy was estimated to extend to adolescence [23]. Survival rates have been reported up to midlife [32].

The advances in treatments and long-term management of children diagnosed with long-term conditions have enabled their survival into adulthood as illustrated in this discussion. The improvements described of the selected long-term conditions profiled here are indicative of hopeful yet realistic expectations for the future for children with long-term conditions.

Age Parameters and Pediatric Policies of Care

As described in this section, the age parameters defining the pediatric scope of practice for children and adolescents has undergone major revisions since the organizational inception of pediatrics. The formalization of the defining boundaries of pediatric care has been an influencing factor for understanding long-standing perspectives toward aging adolescents and young adults.

Beginning in 1938 and subsequently, pediatrics has delimited the age parameters for clinical practice. The earliest age parameters were identified in 1938, and "the practice of pediatrics begins at birth and extends well into adolescence and in most cases it will terminate between the sixteenth and eighteenth year of life (AAP [2, p. 266] as cited in AAP [3, p. 463]). In 1972, the age range of pediatric care was expanded with this statement: "The responsibility of pediatrics may therefore begin during pregnancy and usually terminates by 21 years of age" (AAP, Council on Child Health [40, p. 463]). The age limit of 21 was reaffirmed in 1988 with the proviso that care could be extended beyond age 21 for those with a chronic illness or disability "…if mutually agreeable to the pediatrician, the patient, and when appropriate the patient's family…" (AAP, Council on Child and Adolescent Health, [4, p. 738]).

The most recent AAP statement, Age Limits of Pediatrics, published in 2017 departs from previous policy enumerations of age limitations. This policy document suggests that the upper age limit of 21 "…is an arbitrary demarcation line for adolescence" [26, p. 2]. Instead, this newest policy iteration advocates that specialty care pediatricians consider the condition-related needs of patients rather than the usual terminal age of care at 21 years in circumstances wherein capacity of adult specialty care is limited. Under these circumstances, a hybrid model involving collaboration with primary care providers is encouraged.

This policy change in age parameters is predicated on the revised understanding of adolescent brain development, contemporary societal trends of adolescent and emerging adult development, and the complex care needs of those with SHCN and disabilities [8, 22]. The issue of the clinical capacity of adult providers has been raised repeatedly in the pediatric literature as it pertains to providing specialized

care and understanding of the psychosocial dynamics of living with a childhood-acquired disability/chronic condition [53]. Surveys of specialty adult providers' willingness and preparedness to receive adults with childhood-acquired disabilities/chronic conditions acknowledge the challenges but have referred to issues on the pediatric side that are seen as barriers to promoting the smooth uninterrupted transfer and establishment of care with adult providers. These challenges include insufficient/nonexistent communication initiated by pediatric providers with the adult counterparts and patients who are ill prepared and not health literate to manage and assume responsibilities for their own healthcare needs [16, 57].

Healthcare Transition Policy Initiatives

In its infancy as a practice field and area of study, important initiatives were promulgated that spurred the development of HCT. The professional associations as the American Academy of Pediatrics and the Society of Adolescent Medicine were leaders in calling the attention of not only pediatricians but their colleagues in adult medicine and their interdisciplinary pediatric colleagues of this service need for adolescents and young adults with and without SHCN to effect improved outcomes for these populations. Investments by the federal government were pivotal to spurring the early and ongoing developments in HCT.

Leadership Efforts of Surgeon General C. Everett Koop

Against the backdrop of this significant public health issue, under the leadership of the US Surgeon General, C. Everett Koop, and in collaboration with major pediatric and adolescent health organizations, advocacy groups, and federal partners, HCT for adolescents with chronic conditions was acknowledged as a pressing national service need nearly 40 years ago [13, 34, 45]. Two national invitational conferences were held to address the issue and formulate a national action agenda. The first 1984 HCT conference, *Youth with Disability: The Transition Years*, and, later, the 1989 Surgeon General's conference, *Growing Up and Getting Medical Care: Youth with Special Health Care Needs* brought together the clinical experts from pediatrics, nursing, and psychology; policy analysts; representatives of medical associations and organizations; and state, federal, and private sector administrators to address the national public health issue [13, 34, 45].

The 1989 Surgeon General's meeting explored the scope of the problem as presented by invited experts that included the barriers associated with transition to and the establishment of access to the adult system of care, its financing, and the capacity limitations of interdisciplinary pediatric and adult healthcare professionals to engage in transition services [34, 45]. Several examples of piloted transition programs in the United States were presented as well as the exemplary model of comprehensive services and supports for individuals in the Netherlands that included

healthcare, employment training and placements, housing, and community living. The action plan generated by this conference included:

- Development of care guidelines for transition services
- Exploration of options for reimbursement for transition services
- Development of transition service models based on a family-centered care framework
- Provision of education and training on transition for interdisciplinary healthcare professionals to enhance capacity and competence
- Research to develop and implement evidence-based transition models

HCT Initiatives of Pediatric and Adolescent Organizations

Several years later in 1993, a position paper on transition was produced by the Society of Adolescent Medicine, entitled *Transition from Child-Centered to Adult Health-Care Systems for Adolescents with Chronic Conditions* [13]. This landmark publication, one of the most highly cited publications on the topic, contained an overview of the research and practice in this emerging field of HCT. As acknowledged in this article, there were few service models implemented and tested, limited in part by the paucity of research conducted at the time. For example, the authors noted "Adequate measures exist; however, they have not been used in any study of transitional programs" (Blum et al., p. 570). Of note, the definition of transition offered in this publication has become predominant as a conceptual explanation, "…as the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented health-care systems" [13, p. 570]. This early definition of HCT focused on the transfer procedure associated with HCT process.

Later, in September 1994, an invitational conference on transition entitled *Moving On: Transition from Pediatric to Adult Health Care* was hosted [12]. The purpose of this conference was to convene an international group of experts in adolescent and adult care who had experience with transition. Commissioned papers from this conference appeared in the *Journal of Adolescent Health* that addressed pertinent issues on HCT. Of interest, one of the earliest clinical commentaries, entitled *Between Two Worlds: Bridging the Cultures of Child Health and Adult Medicine*, authored by an internist appeared in this issue [61]. This was one of the first articles published by a non-pediatric professional pertaining to HCT. The cultural contrasts between these divergent service models were explicated in terms of the challenges associated with the transfer of care. Conference recommendations focused on implications for service, training, quality improvement, and research. Importantly, transition was conceptualized not as an event, but rather as a long-term process beginning at diagnosis based upon a family-centered framework of care. Interestingly, the four models of care highlighted for recommendations were based on joint service models involving pediatric and adult providers that focused on the transfer process: (a) disease specific; (b) generic; (c) primary care; and (d) single site (Box 1.1).

Box 1.1 Early Proposed Models of Care

Disease specific	Transfer of care is initiated in the pediatric specialty program followed by joint team/clinic of pediatric and adult specialty providers before transfer to the adult specialty service.
Generic	Transfer of care is coordinated by the primary care pediatrician in consultation with specialty providers followed by the transfer to adolescent primary care team in consultation with specialty providers followed by transfer to internist who coordinates care with referrals to specialty providers.
Primary care	Care is coordinated by general practitioner in consultation with pediatric and adult specialty care providers as consultants.
Single site model	The continuum of care is provided in one setting: seamless healthcare organization.

Summary of Recommendations [67]

In 1996, the American Academy of Pediatrics issued its first policy statement on HCT, jointly authored by the Committee on Children with Disabilities and the Committee on Adolescence [6]. Unlike the Society of Adolescent Medicine's position paper published in 1993, this document did not define HCT. Rather, issues pertaining to achieving developmental milestones associated with adulthood and the pediatrician's role in facilitating their achievements were presented. Practice responsibilities of pediatricians for transition planning and support were enumerated such as strategies to use in promoting the adolescent's independence pertaining to self-care, community living, and fiscal matters. Postsecondary goals associated with education and employment were identified as relevant pediatric practice concerns in providing guidance and resource information to adolescents and their families. Pragmatic discussions pertaining to insurance coverage once eligibility for pediatric coverage terminates and enrollment/redetermination in various Social Security Administration programs such as Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI) were covered.

Ambiguity is evident in this early policy statement as it pertains to hospitalization during this period of transition from pediatric to adult care, as several recommendations were offered to address the needs of the new population of patients for providers who had limited clinical experience in the provision of their care [6]. An evident recommendation is made for training of adult staff involved with inpatient care of adolescent/young adult patients with SHCN involving condition management. A period of joint management by the pediatrician and adult provider is suggested during the period of transition to care provided solely by adult healthcare providers. Another yet uncommon recommendation is suggested that primary care pediatricians "..seek admitting privileges to the adult unit to ensure their continuing participation as the primary attending physician or as a consultant" [6, p. 1205]. Of importance during this period of transition is the adolescent's/young adult's full participation and involvement in transition planning that is based on their preferences and needs.

HCT Consensus Statement

A turning point was achieved in policymaking in the HCT field with the publication of the first consensus policy document, entitled *A Consensus Statement on Health Care Transitions for Young Adults with Special Health Care Needs* issued by the AAP, American Academy of Family Physicians (AAFP), and American College of Physicians (ACP)-American Society of Internal Medicine (ASIM) [5]. Although the agreed-upon recommendations were circumscribed, the ramifications were significant. The *Consensus Statement* provided a collective acknowledgement of necessity to facilitating the transfer of care for young adults with SHCN from pediatric to adult care. Furthermore, there was collaborative agreement that this process required informed and skilled professionals involved in the process on both sides – the sending and receiving ends of the process. The importance of this *Consensus Statement* was the collective involvement of major pediatric and adult professional associations to craft an agreement and acknowledgement of this field of practice and the necessity of moving forward to craft new models of collaboration to effect improved outcomes for adolescents and young adults with SHCN.

2011 Clinical Report Issued by AAP, AAFP, and ACP

Nearly a decade later, this professional coalition composed of the AAP, AAFP, and ACP published clinical practice guidance, the *Clinical Report*, for implementing HCT services for youth and young adults [7]. Of clinical relevance, although the preceding *Consensus Statement* was directed specifically to address the clinical challenges of youth and young adults with SHCN's HCT from pediatric to adult health care, this *Clinical Report* was broader in scope. This clinical algorithm was designed for application for *all* youth and young adults including those with SHCN. This algorithm of the clinical guideline, based upon a patient and family-centered model of primary care, included three dimensions of practice-preventive care, acute illness care, and chronic condition management (CCM). Developers of the algorithm noted that this guide could be applied to specialty practice as well. This *Clinical Report* was designed not only as an algorithm for the provision of HCT services, but importantly serves as the template from which subsequent AAP publications are developed pertaining to this field of practice, research, and quality improvement.

Noteworthy elements of the *Clinical Report* begin with the distinction between transition and transfer of care. The transition process as enumerated in this document is a lengthy process of clinical monitoring, service coordination and referral, and youth and young adult education to foster health literacy and CCM. Unlike the previous *Consensus Statement* wherein the age range focused on the transfer of care period, the *Clinical Report* recommended the age of 12 for initiating HCT, although an earlier age for youth with SHCN is cited as appropriate [7].

For the first time, the algorithm of the *Clinical Report* provided concise guidance as to the action steps to be undertaken along the developmental continuum to foster and support the youth's and young adult's transition and transfer of care. Previously, guidance published by pediatric and adolescent medicine professional associations broadly stated areas of practice emphasis pertaining to this new and developing field of care for the ever increasing youth and young adult population with SHCN. This *Clinical Report* also directed attention to the roles and responsibilities of the adult medical home providers who receive youth and young adults. Paramount considerations of the transfer procedure are the identification of adult providers who are prepared to receive the generational group of adolescents and young adults and the transmission of medical information to new service providers so as to proceed smoothly and competently with care.

2018 Clinical Report *Issued by AAP, AAFP, and ACP*

More recently, an update of the 2011 *Clinical Report* was published in 2018 [69]. This *Clinical Report* revision reflects more current developments in the field with the proliferation of literature now being generated as evident with the research being produced using more rigorous designs and methodologies (refer to State of Research, Clinical Practice, and Beyond for additional information).

The 2018 *Clinical Report* provides new attention to the *Six Core Elements for Pediatric and Adult Care* (described in greater detail below), enlarged scope of HCT practice, special populations, reimbursement options, and training resources for pediatric and adult providers who provide services to youth and young adults with SHCN. These recommendations reflect the progress and development in the HCT field.

Federal Initiative: Title V Programs for Children with Special Health Care Needs

In this section, several federal initiatives will be presented that have influenced the need for and served to foster the development and implementation of HCT resources and service models in the United States. This review will begin with the establishment of the Crippled Children's Service, a federal program in 1935, described in detail below and conclude with current resources available for youth and young adults, families, and healthcare and non-healthcare professionals.

Title V Programs for Children with Special Health Care Needs

There are many federal programs whose mission is to address the needs of children, adolescents, and young adults with SHCN. Foremost, among these programs is the Title V Program, a block grant program of the Maternal Child Health Program of the US Department of Health and Human Services. Historically, the Title V Program was first established in 1935 through the authorization of the Social Security Act in Title V of the legislation that allocated block grant funding to states for health and welfare services for women and children that included maternity and infant care. A portion of Title V funding was allocated for children with chronic conditions, then known as the Crippled Children's Service (CCS) [9, 30]. The vast majority of children initially served through CCS had orthopedic impairments; subsequently other diagnostic groups of children were served that included those with congenital heart disorders and rheumatic fever [31].

Fifty years later in 1985, with the passage of Public Law (PL) 99-272, the name of Crippled Children's Service was changed to the Program for Children with Special Health Care Needs (CSHCN). Later, amendments to the Title V were effected in the Omnibus Budget Reconciliation Act (OBRA) (PL 101-239) in 1989 which expanded the mission of the program. These programmatic changes required states to allocate 30% of the block grant funds for children with SHCN. Concomitant with this requirement was the directive to create a system of care that would better serve this population of children, youth, and their families. This new provision stipulated that the service system was to provide care that was family-centered, community-based, and coordinated [29, 30].

In an effort to create greater accountability of the grant funding provided, new reporting requirements were enacted in the (OBRA) of 1989 [33]. These new programmatic guidelines specified that a system of performance standards incorporating measurable metrics (i.e., annual goals) to monitor progress with Title V Maternal and Child Health Services Block Grant funding be established at the federal level by the Maternal and Child Health Bureau (MCHB). Initially, 18 National Performance Measures (NPM) (later reduced to 15) were developed that were based upon the legislative requirements of the Title V Programs. The 1997 programmatic areas covered maternal child health, adolescent services, and CSHCN. Each of the 50 states, the District of Columbia, and the 9 territories selected 8 NPM from the list of 18 NPM. Concurrently with the development of NPM for all of the Title V Programs, the Maternal and Child Health Bureau (MCHB) formulated six core outcomes for CSHCN. These initial core outcomes were integrated in the NPM for CSHCN listed in Box 1.2.

Box 1.2 Core Outcomes for CSHCN

No.	Core Outcomes
1.	Families of SCHCN will partner in decision-making and will be satisfied with the services that they receive.
2.	CSHCN will receive coordinated, ongoing, comprehensive care within a medical home.
3.	Families of CSHCN will have adequate private and/or public insurance to pay for the services that they need.
4.	Children will be screened early and continuously for special healthcare needs.
5.	Community-based service systems will be organized so that families can use them easily.
6.	Youth with special healthcare needs will receive the services necessary to make transitions to adult life, including adult health care, work, and independence.

McPherson et al. [48, p. 1539]

National Performance Measure # 12: Transition

In 2015, the national performance measurement system was substantially revised. Transition continues as one of the NPM as it was "…considered crucial to the development of a well-functioning system of care for children with special health care needs" [33, p. 950]. However, the revised transition NPM is more inclusive in scope in terms of addressing the entire adolescent population but more narrowly focused on health care in contrast to earlier NPM, which was broader as work and independence were addressed: NPM # 12: *Transition (percent of adolescents with and without special healthcare needs who received services necessary to make transitions to adult health care)*. The rational for delimiting the scope of this NPM was the extent to which it could be measured with an accessible and reliable data source.

Currently, there are 36 states and territories that have selected NPM # 12: Transition as a NPM as presented below in Box 1.3.

Healthy People: National Health Report Cards and CSHCN

Healthy People (HP) reports of 2000, 2010, and 2020 provide the template for guiding and assessing the nation's progress in achieving health goals and objectives of pertinence to the US public [56]. Hence, the HP reports are broad and comprehensive in scope as health issues of concern for the American public across the lifespan are addressed. Beginning in *HP 2000*, objectives for CSHCN were integrated as objectives and targets for achievement. The objectives as described below from 2000 to 2020 were closely linked with the federal legislation Omnibus Budget Reconciliation Act (OBRA) (PL 101-239) in 1989 and interagency efforts with the

Box 1.3 States and Territories Selected Transition as a NPM

Alabama, Arizona, Arkansas, California, Connecticut, District of Columbia, Federated States of Micronesia, Florida, Georgia, Guam, Hawaii, Illinois, Indiana, Iowa, Kentucky, Marshall Islands, Maryland, Massachusetts, Michigan, Minnesota, New Jersey, New Mexico, New York, North Dakota, Oklahoma, Oregon, Puerto Rico, Rhode Island, Tennessee, Texas, Utah, Vermont, Virgin Islands, Virginia, Wisconsin, Wyoming

US Department of Health and Human Services, Health Resources and Services Administration's Maternal and Child Health Bureau (n.d.)

Health Resources and Services Administration's Maternal and Child Health Bureau. Over the years as described below, the refinement of objectives for CSHCN and more specifically for HCT has undergone revision.

Healthy People 2000

Based upon Public Law 101-239 OBRA of 1989, the Title V Programs for Children with Special Health Care Needs were now required to develop and implement systems of care for "… the promotion and provision of family-centered, community-based, coordinated care for children with special health care needs;" and "outpatient and community-based services programs for children with special health care needs provided primarily through inpatient institutional care." Additionally, 30% of the funds of the Maternal and Child Health Block Grant Program were to be allocated for CSHCN. These new programmatic requirements resulted in the addition of the following *Healthy People (HP)* Objective in 1990 – 17.20: *Increase to 50 the number of States that have service systems for children with or at risk of chronic and disabling conditions, as required by Public Law 101-239* [51]. This objective reflected the philosophical shift in supporting a different model of care for CSHCN that was more family-focused, accessible, and community-based. This model of care exemplified the changing patterns of the CSHCN lived experience as the advances in medical treatment and interdisciplinary care resulted in improved survival rates.

Healthy People 2010

The *2000 HP* Objective (17.20) was revised with an operational definition that was focused on children rather than the systems of care. This revised HP 2010 objective now read: *Increase the proportion of children with special health care needs who receive their care in family-centered, comprehensive and coordinated systems.* Both the MCHB and Centers for Disease Control and Prevention collaborated in the

revision of this objective. The NS-CSHCN and NSCH, funded by the Health Resources and Services Administration's Maternal and Child Health Bureau, were the data sources for measurement of progress as presented in section "National Surveys to Monitor Transition Core Outcome for CSHCN" of this chapter [48].

Healthy People 2020

The transition objective of *HP 2020* was revised again as major efforts were made to only include objectives that could be measured and compared to measurable outcomes. Objectives and sub-objectives of previous *HP* documents were eliminated wherein data sources do not exist that enable measurement of progress and/or achievement in meeting the stated objectives. Transition is one of the sub-objectives (DH-5) of the *HP 2020* Disability and Health Topic Areas and states: *Increase the proportion of youth with special health care needs whose health care provider has discussed transition planning from pediatric to adult health care.* The data source for obtaining measurements of this objective has been the NS-CSHCN, HRSA/MCHB, and NSCH of CDC. For additional information on data measurement, refer to section "Federal Initiatives to Promote Health Care Transition" as changes have been enacted to obtain more objective measurement data on this objective.

National Surveys to Monitor Transition Core Outcome for CSHCN

In recognition of the necessity to measure progress with achieving the six core outcomes, MCHB embarked upon the development of national surveys to monitor the national- and state-level progress of children's health. The NS-CSHCN was initially designed to track progress with the five of the six core outcomes (Outcomes 2–6 in Table 1.1). NSCH monitored # 1 core outcome (Table 1.1) as well as children's physical and mental health, access to care, and data on the child's community [20]. The evolution of surveys used to collect data on the transition core outcome is described below.

2001 NS-CSHCN Survey Baseline Data of Six Core Outcomes for CSHCN

Monitoring systems were established by MCHB to track the progress with meeting these outcomes during the forthcoming decade (2001–2010) with two new national surveys: the National Survey of Children with Special Health Care Needs

Table 1.1 Core outcomes for CSHCN

No.	Core outcomes	Baseline data 2001 NS-CSHCN and 2001 NHIS meeting outcome criteria
1.	Families of SCHCN will partner in decision-making and will be satisfied with the services that they receive	57.5%
2.	CSHCN will receive coordinated, ongoing, comprehensive care within a medical home	52.6%
3.	Families of CSHCN will have adequate private and/or public insurance to pay for the services that they need	59.6%
4.	Children will be screened early and continuously for special healthcare needs	51.6%
5.	Community-based service systems will be organized so that families can use them easily	74.3%
6.	Youth with special healthcare needs will receive the services necessary to make transitions to adult life, including adult health care, work, and independence	5.8%

McPherson et al. [48, p. 1539]

(NS-CSHCN) and the National Survey of Children's Health (NSCH). NSCH was used to measure progress with Core Outcome 1; NS-CSHCN measured the remaining five core outcomes [48]. The 2001 National Health Interview Survey (NHIS) was employed initially to gather data on Outcome 1.

For each of the outcomes, criteria were operationalized that had to be met to be considered achieved as indicated by survey respondents for youth ages 13–17 years. For Outcome 6, respondents needed to affirm the following two components:

1. Received transition guidance and support
   (a) Doctors discussed changes associated with adulthood.
   (b) Plan developed to address changing needs.
   (c) Transfer of care to adult providers discussed.
2. Received vocational/career training

As noted in the baseline data gathered for the six core outcomes, Outcome 6 was the least achieved of all of the outcomes (Table 1.1).

Table 1.2 presents the findings associated with the components of the transition core outcome reported from the 2001 NS-CSHCN Survey. Less than 20% (15.3%) of respondents indicated having received guidance as described in component 1; 25.5% replied that vocational/career training had been received (Table 1.2).

Additional analysis of this data was reported as associated with race/ethnicity. There were significant differences by race/ethnicity of those who reported doctors discussed changes associated with adulthood. Just 31.6% of Hispanic respondents reported these discussions with their physicians compared to 52.1% non-Hispanic whites, 49.9% non-Hispanic blacks, and 49.9% non-Hispanic other race/ethnicity ($p = .00016$) [42]. Other ethnic/racial significant differences in patterns of responses were noted as well. When asked if discussion had ensued about the transfer to adult

Table 1.2 Transition core outcome and components based on the 2001 NS-CSHCN Survey

	Percent achieved
YSCHN achieved transition core outcome	5.8%
Components	
Received guidance pertaining to healthcare aspects of transition	15.3%
Transfer of care to adult providers discussed	41.8%
Doctors discussed changes associated with adulthood	50%
Plan developed to address changing needs	59.3%
Received vocational/career training	25.5%

McPherson et al. [48]

providers, non-Hispanic blacks (38.1%) and non-Hispanic whites (40.6%) differed significantly from Hispanics (56.4%) and non-Hispanic others (58.8%) ($p = .03$).

The percentage of older adolescents (16–17 years) (19.5%) reporting affirmatively to meeting the transition core outcome was significantly higher than for younger adolescents (13–15 years) (12.9%) ($p = .001$). Significant differences were reported for adolescents meeting the transition core outcome who reported having a medical home (20.1%) compared to those who did not (11.4%) ($p = .000$) [42].

2005–2006 NS-CSHCN Survey Findings

Data were gathered again with the 2005–2006 NS-CSHCN Survey to assess the extent to which progress had been achieved with the six core outcomes. Core Outcome 6 was measured differently in the 2005–2006 Survey. There were variations in the item measuring the transition outcome. The vocational and career training component was excluded and discussion about health insurance coverage was added [43]. Queries were added about encouraging the youth to self-manage and assume responsibility for their care needs, and future planning for health needs as an adult was explicated. As with the earlier 2001 NS-CSHCN Survey, all elements had to be met to affirm the youth had received transition guidance and support: (a) transfer of care to adult providers; (b) doctors discussed changes associated with adulthood; (c) changes with insurance coverage as an adult; and (d) assumption of self-management responsibilities encouraged. Findings associated with the transition outcomes were as presented in Table 1.3.

As with the earlier national survey, NS-CSHCN, the transition core outcome lagged behind the other CSHCN core outcomes. However, comparisons between the earlier 2001 NS-CSHCN and 2005–2006 NS-CSHCN are difficult to make as the items were changed during the interim period of time. Of note, significant disparities were again found among groups surveyed. Findings revealed that 47.6% of non-Hispanic white youth, ages 12–17, attained the transition core outcome compared to 28.7% non-Hispanic black youth and 26.3% Hispanic youth. The odds of

Table 1.3 Transition core outcome based on 2005–2006 NS-CSHCN Survey

	Percent achieved
YSCHN achieved transition core outcome	41%
Components	
Transfer of care to adult providers	42%
Doctors discussed changes associated with adulthood	62%
Changes with insurance coverage as an adult	34%
Assumption of self-management responsibilities encouraged	78%

Lotstein et al. [43]

not achieving the transition core outcome was 1.5 and 1.43 times greater ($p \leq .05$) for non-Hispanic black and Hispanic youth, respectively [43, 44]. A number of factors were identified as contributory to these disparities, which included access to health insurance, living in low-resourced communities, and sociocultural factors such as educational level and attitudes toward future planning and healthcare providers.

2016 National Survey of Children's Health Findings on Healthcare Transition Planning

In 2016, the National Survey of Children's Health (NSCH) was conducted that gathered data from a representative national survey of 50, 212 children and youth, 0–17 years, of whom 20, 708 were ages 12–17. The 2016 NSCH integrated for the first time previous NSCH and National Survey of Children with Special Health Care Needs (NS-CSHCN). This survey was designed to collect comprehensive data on children's and youth's physical and mental health, demographic data including parents/caregivers and the child's social network (i.e., school and community) [20]. Items included queries pertaining to children and youth with special healthcare needs such as health insurance, access to care, and chronic care management.

Data on the progress of facilitating the HCT of adolescents with/without SHCN were gathered as well. Parents/caregivers of adolescents ages 12–17 were asked questions that corresponded with the NPM and the 2011 Clinical Report guidelines [38]. The measure of transition planning as reported in the 2016 NSCH is a composite score based on the four survey items: (a) speaking privately with the provider during the preventive care visit; (b) transfer of care to adult provider; (c) changes associated age 18 (in some states, considered the age of majority); and (d) self-management instruction. Items c and d were combined for data analysis purposes as "provider active work with youth" [38, p. 3]. The scoring of youth as receiving HCT services was based upon affirmative responses to all three items. Findings revealed 17% of YSHCN and 14% of youth without SHCN received all elements of

HCT. Higher percentage of YSHCN (23%) and those without SHCN (18%) ages 15–17 received HCT services as compared to those age 12–14 years. Those who reported receiving care coordination and written care plan were more likely to report having received HCT services [38]. As the NSCH findings demonstrate, much work is needed to ensure that all youth receive the HCT services needed to facilitate their uninterrupted transfer of care to adult services and to have them well prepared to function as informed, literate consumers of health care and to function independently as possible in managing their own healthcare needs.

Federal Initiatives to Promote Healthcare Transition

Beginning in the late 1990s, the Health Resources and Services Administration's Maternal and Child Health Bureau allocated funding to support the development of community-based HCT demonstration projects and national resource centers. This section provides an overview of those efforts that have been undertaken for the past two decades.

Healthy and Ready to Work

In the mid-1990s the Division of Children with Special Health Care Needs, Maternal and Child Health Bureau, launched a national initiative in HCT, entitled *Healthy and Ready to Work (HRTW)*. The initial effort was directed to funding innovative community-based pilot programs in HCT. Each of the funded projects was involved with outreach training for interdisciplinary colleagues from health and non-health organizations, provision of technical assistance to interagency providers, and development of HCT resources for dissemination to diverse constituents that included adolescents with SHCN, families, service providers, and policymakers. Each of the projects was unique in their goals and objectives although they shared commonalities of purpose. Two cycles of funding were available for these early pilot projects. It was during this time funding was allocated for a national HCT resource center. This first center, *Healthy and Ready to Work (HRTW) National Center*, was established in 2001 and was the precursor resource center of *Got Transition.*

National Resource Center for HCT: *Got Transition*

Got Transition serves as a comprehensive HCT resource center funded by the Maternal and Child Health Bureau. Its website contains resources for youth and families, researchers and policymakers, and healthcare providers. *Got Transition* staff are active in the development and dissemination of HCT resources, compiling

a repository of HCT evidence and research conducted and providing technical assistance to systems of care in developing HCT service models. *Got Transition* in conjunction with the Maternal and Child Health Bureau has undertaken policymaking efforts to promote the development of HCT services within the pediatric systems of health care.

Of relevance to the development and implementation of HCT services in healthcare service setting is a guideline template to provide guidance in the elemental components of establishing a model of care. This guideline template is referred to as the Six Core Elements of Transition 2.0 (Got Transition, 2014). The Sixth Core Elements include (a) the establishment of a HCT policy that specifies the benchmarks of services provided; (b) establishment of a monitoring system that enables tracking of the youth's and young adult's progress in achieving HCT predetermined goals; (c) use of a transition readiness assessment to monitor acquisition of HCT skills and knowledge; (d) development, implementation, and evaluation of HCT adolescent-centered plan that is based upon individualized needs focused on the transfer of care process; and (e) initiation of the transfer process that includes the confirmation that care has been transferred and established with adult providers.

Development of the HCT Field of Science and Practice

Healthcare Transition Research Consortium

In 2008, a group of colleagues, the early "pioneers" in the field of HCT, understood the wisdom and necessity of networking together and creating a forum wherein their work, questions, and experiences could be shared. These early visionaries were led by Maria E. Diaz-Gonzalez de Ferris, MD, MPH, PhD, and David L. Wood, MD, MPH, and under their leadership established the Health Care Transition Research Consortium (HCTRC). Initially, conference calls were scheduled to informally share information and provide updates pertaining to research and practice efforts. Concomitantly, small gatherings were held at the University of North Carolina, Chapel Hill, to discuss HCT topics of interest and current research projects underway.

Four year later, in 2012 HCTRC partnered with the Baylor College of Medicine and Texas Children's Hospital that had been hosting, under the leadership of Dr. Albert Hergenroeder, the annual HCT conference entitled *Chronic Illness and Disability Conference: Transition from Pediatric to Adult-Based Care* since 1999. That partnership enabled the hosting of the annual HCTRC Research Symposium held in conjunction with the annual Transition from Pediatric to Adult-Based Care conference. The symposium draws well-known international and national speakers to present their research and network with one another. It is the only research forum in the United States devoted solely to HCT. Another research forum, inspired in part by the HCTRC Research Symposium, has now been hosted in Switzerland.

Under the leadership of HCTRC members, a number of endeavors have been undertaken to promote the relevancy and importance of HCT as well as direct attention to this field of practice and research. Under the editorship of Drs. Wood, Ferris, and John Reiss, (inaugural members of HCTRC and early HCT "pioneers") an entire issue entitled *Youth Health Care Transition* was published in the *International Journal of Child and Adolescent Health*. This publication was a landmark development as it was the first time that an entire issue had been published on the topic of HCT which was composed of 16 review and research articles.

Other articles were published by the HCTRC Consortium, which included HCTRC HCT model to guide practice and research [11] and Delphi survey to identify HCT outcomes [24]. Each year HCTRC sponsors a Special Interest Group, Health Care Transition, and Self-Management at the annual Pediatric Academic Societies meetings. Other ongoing activities include monthly conference calls involving Consortium members nationally and internationally that enable them to share their work, updates, and pending events of interests and information about the annual HCTRC Research Symposium.

This consortium has done much to foster the development of the field of practice and research through these activities. HCTRC has been the sole network dedicated solely to a number of efforts to realize its mission. HCTRC has been engaged in promoting dissemination of research currently produced, facilitating updates on current developments in the field of HCT as it pertains to legislative, policymaking, and research initiatives and enabling networking among colleagues involved with HCT research, quality improvement, and scholarly efforts.

State of Research, Clinical Practice, and Beyond

In 2004, the first comprehensive narrative HCT review of literature was published. This early review covered a span of 21 years from 1982 to 2003 and included 43 studies. These early studies lacked rigorous designs and methodology. The research designs were primarily descriptive; none of the studies included comparison or control groups. None of the studies reported the use of tools with needed psychometric measurements of validity and reliability. The topical foci of studies of this review examined adolescent and parental HCT needs, HCT barriers, and transfer criteria. However, these studies represented the emerging field of practice and science and provided early guidance and recommendations for subsequent practice and research [10].

Since that early narrative review, the volume and quality of research conducted are apparent with the publication of HCT systematic reviews that provide critical analyses of HCT studies on selected topics (i.e., examination and analysis of HCT outcomes). A recent review of systematic reviews reported a total of 37 systematic reviews involving 71 studies that met eligibility criteria that have been conducted to date since 2004 [27].

Major findings of the review reported the following: More than half of the reviews have been published since 2014. Quantitative synthesis was lacking in

all but one of these reviews; one review reported meta-analysis of four studies within the larger review that was qualitatively focused [63]. Using the AMSTAR criteria for assessment of the quality of the reviews, 12 of the 37 studies were considered to be high-quality reviews [65]. Four randomized control trials were reported in reviews. The reviews represented divergent areas of focus. Although 20 of the 37 were not diagnostic focused, of those that were, type 1 diabetes was the focus of 7 reviews, and 2 were conducted on mental health. Exploration of transition interventions was conducted in 14 reviews. As noted, 14 (19.7%) of the 71 studies addressed interventions associated with adult care following the transfer of care.

The limitations evident in the reviews were the variability in the quality of the reviews. Several components considered essential in quality reviews were missing such as publication bias, quality assessment metrics of studies reviewed. Just one of the reviews was registered in PROSPERO, a website that provides a listing and status report of systematic reviews being conducted.

A recent systematic review with updated examination of HCT outcomes following an earlier systematic review was conducted by the members of the authoring team with studies published between May 2016 and December 2018 [25, 62]. Nineteen studies were included in this review. Examination of the HCT interventions was based upon the 2018 AAP/AAFP/ACP Clinical Report Guidelines [69]. The studies included in this review reflected an international perspective as five (26%) were conducted in the United States, four in Australia, three in Canada, and two in the Netherlands. As reported in the Hart et al. review [27], the most frequently cited condition reported was type 1 diabetes. Other chronic conditions reported were congenital heart disease, inflammatory bowel disease, juvenile idiopathic arthritis, and kidney transplants. The Triple Aim framework was used to report outcomes [70]. The following positive outcomes were reported according to this framework: population (11; 65%); patient experience (1; 5%); and utilization of care (6; 60%). All studies reported the transfer of care assistance; nearly all referred to one transition planning activity (i.e., patient education; medical summary) and integration into adult care (i.e., follow-up on first appointment with adult provider).

The Effective Public Health Practice Project Quality Assessment Tool for Quantitative Studies to assess the quality of studies is included in the review [68]. Study strengths were reported as follows: two studies as strong (11%); ten studies as moderate (53%) and seven as weak (37%). Noteworthily, 74% of the studies did not report the psychometrics of the tools used for measurement; 58% did not have sufficient controls for confounding variables (i.e., lack of randomization).

As evident with the growing body of HCT literature, the studies being reported are contributing to an improved understanding of the phenomenon of HCT. As this body of evidence evolves, issues as to the design and implementation of strategies that effect positive biopsychosocial and health outcomes for adolescents and young adults with chronic conditions will be better understood. As reported in the most current reviews of the literature, the science is slowly emerging that will assist with the development of service models that improve outcomes of care, are cost-effective, and meet with the satisfaction of the consumers who use them [70].

Conclusion

This chapter provided an overview of the development of the healthcare transition field of practice and science since its initial emergence as a service need for the growing population of adolescents and young adults with chronic conditions and disabilities 30 years ago. As has been detailed in this chapter, government investment, visionary leadership, and the advocacy and support of professional medical associations were pivotal agents of change in providing the impetus needed in fostering the growth of this important area of practice and research. As delineated in this chapter, the past efforts recorded here have led to the steady movement forward in shaping new and innovative models of service that will better serve this population of youth and young adults.

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