



# The International Perspective on Healthcare Transition

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Beth E. Anderson, Swaran P. Singh,  
Claire Stansfield, and Kristin Liabo

## Introduction

Adolescence is a period of development typically agreed to start around the age of 10 and to extend into early adulthood [1]. There are approximately 1.2 billion adolescents globally [2]. The bulk of the youth population is in low- and middle-income countries with poor access to health care [3]. In the United Kingdom (UK), young people aged 10–19 account for 11.4% of the population (equating to 7.4 million adolescents) [4]. In the United States (USA), this figure is estimated at 13.8% (42.7 million) [5]; in Canada, 11% (4 million) [6]; and in Australia, 12.2% (2.9 million) [7]. The value of engaging adolescents in positive health behaviours is well-established [3, 8, 9]. Such activity aims to mitigate negative health outcomes both for young people themselves and for any children they go on to have [2, 3]. As users of health care, adolescents are a distinct

group with distinct care needs [10, 11]. While comparable cross-country data on health indicators and service use is limited [9], available figures indicate that in the U.S.A. alone, approximately three-quarters of a million young people enter adulthood with conditions that need (or are likely to need) input from health services [12]. Many of them will need their care transferred from children's to adults' health services.

This chapter focuses on health-care transition (HCT), a relatively under-researched area, in contrast to the wealth of literature on adolescence more generally. Developmental transition is referred to but only as an important element of the context for health-care transition. After summarising briefly the history of transition-specific care, we provide an overview of the extent of poor transition in high-income countries globally and an analysis of the reasons for this. We then describe how to deliver effective transition support, specifically the overarching principles of care that should apply, irrespective of the approach taken, and three emerging models of practice that have been associated with positive impacts. We conclude by identifying gaps in the literature and implications for future research and practice.

The chapter is informed by, and extends, a series of systematic reviews on supporting adolescents and young adults with special health-care needs (AYASHCN) through transitions from children's to adults' health services. The reviews

B. E. Anderson, Ph.D.  
Social Care Institute for Excellence, London, UK  
e-mail: [beth.anderson@scie.org.uk](mailto:beth.anderson@scie.org.uk)

S. P. Singh, M.B.B.S., M.D., D.M., F.R.C.P. (✉)  
University of Warwick, Coventry, UK  
e-mail: [s.p.singh@warwick.ac.uk](mailto:s.p.singh@warwick.ac.uk)

C. Stansfield, M.Sc.  
University College London, London, UK  
e-mail: [c.stansfield@ucl.ac.uk](mailto:c.stansfield@ucl.ac.uk)

K. Liabo, Ph.D.  
University of Exeter, Exeter, UK  
e-mail: [k.liabo@exeter.ac.uk](mailto:k.liabo@exeter.ac.uk)

are complemented by a supplementary search conducted by the authors to identify recent lessons from emerging international practice.

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### Transition-Specific Support: A Brief History

The importance of providing age-appropriate, targeted support for adolescents moving to adults' services was first articulated in the mid-1980s at an international conference in the U.S.A. [13]. The evident gap in this provision was attributed to advancements in health care enabling more young people with childhood-onset conditions to live to adulthood [13]. This increase in life expectancy is predicted to continue across a range of chronic health conditions [14], meaning more young people will move out of paediatric care and into adults' services for long-term support. This is happening in the context of a conceptual and operational divide between children's and adults' health-care practice, the corollary of increased clinical specialisation over recent decades. The evolution of this focus on specialty-specific competence has varied from one area of medicine to another, reflecting the diversity of financial, social and political drivers on different parts of the system. Accordingly, the imperative to improve the support offered to young people with health conditions, before, during and after their move to adults' services, has been a feature of policy in a number of high-income countries over recent years [15, 16]. Such policy, however, has not led to system-level planning and provision, and poor transition care is commonplace [17].

Many young people do not experience successful transition or are simply transferred from one service to another without any introduction as to how adults' services operate and what is expected of adult patients. Fewer than 50% of young people with special health-care needs in the U.S.A. receive the support they needed at this critical stage of their care journey [18]. Poor transitions can result in significant costs to young people themselves and to the wider health economy. A recent analysis from the UK costed poorly managed transition for a young person with a

lifelong condition (diabetes) at £9.94 m (equating to approximately \$13.4 million) [19].

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### The Context for Service Transition

The multi-faceted nature of young people's transition is complicated by the fact that transition as a concept is inconsistently defined and applied. Transition (a managed process taking place over time), in practice, can be made synonymous with transfer (a discrete event at a single point in time at which responsibility for care moves from one provider to another), in spite of broad understanding in the health-care community that this is not the case [18]. As a result, young people can find themselves in the adults' service with little warning, or worse, facing a future in which there is no formal support available to them.

Transition is complicated further by the fact that it is not a process that occurs in isolation. Firstly, service transition is set against a backdrop of young people's wider developmental transition (see Chaps. 2 and 3). Adolescence is a pivotal time in a young person's life, during which they experience multiple physical, cognitive, social, emotional and behavioural changes [1]. These can be difficult to deal with, in and of themselves and can also increase risk of psychosocial or condition-specific problems [20]. There is emerging research that suggests differential maturation of the areas in the brain controlling emotional and rational aspects of development [21], which might explain that some young people start to take greater risks and be more impulsive [21] (see also Chaps. 2 and 3). It might also explain why this is a period when serious mental disorders can emerge [11]. Practitioners can therefore find it difficult, or feel insufficiently skilled, to engage this group of people—no longer treated as children, but not yet treated as adults [22]. There can also be confusion within and between services about when transition starts; that is to say, the age at which it is appropriate to begin planning for the young person's move to adult services.

Secondly, transition between support services is only one type of situational change that young people may experience around this time. Major

life events taking place during late adolescence can come with significant contextual changes, for example, leaving home, starting work or going to university. Such important and potentially stressful occurrences can themselves trigger, or worsen, health conditions. Where such events involve moving from one geographical area to another, and a young person has previously been supported by services in their home area, this can pose an additional barrier to continuity of care.

Thirdly, health systems in developed countries are complex. Moving from children's to adults' services can involve navigating a confusing array of people, places and processes. There are major differences in the culture, ethos and environments of adults' services compared to children's. As a result, it is commonplace for young people and their families to feel unprepared for these changes and to find the process of change confusing and traumatic [23]. The inconsistency of health-care provision and quality across a range of services can become apparent to young people as they move across geographical, service or administrative boundaries. At worst, this can mean there is no adults' service corresponding to that available for children or that higher thresholds for adults' service entry render young people ineligible for any support after the point of transfer. This is particularly pertinent to mental health care [24, 25].

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## Barriers to Transition

Despite the relative profusion of transition-related policies, implementing culture change or service improvement initiatives in any health economy is difficult. This has meant that even when guidance is in place, it fails to translate into good practice [26–29]. Commissioners and practitioners have struggled to ensure young people move from children's to adults' health-care services in a streamlined way, with no gap or delay in provision.

Barriers to transition can be classified as relating to the service level or the individual level. Firstly, let us consider the service level, where lack of available provision is one of the most sig-

nificant barriers; there are simply far more young people moving to adulthood with specific health-care needs than there are suitable services available to support them [30, 31]. Where there are services in place, one of the most significant factors impeding successful transition is the absence of a clear, structured transition model or pathway [32, 33]. Without this, young people and their families can feel unclear about what will happen after they leave children's services and who will support them. In addition, having a clearly communicated process in place ensures that young people are prepared for transfer, rather than this coming as a shock to them—another barrier to successful transition [34].

An additional service-level barrier to transition occurs where practitioners consider health-care support needs in isolation. Evidence on young people's perceptions of the barriers to transition consistently cites, as an example, lack of consideration given by practitioners to lifestyle changes and wider needs (including sexual health, drug and alcohol use, education, employment and social needs) [32]. As these subjects can be sensitive and complex, clinicians can find it difficult to address them with young people [16]. This problem may also be a micro-level manifestation of a macro-level barrier, specifically, poor inter-agency and intra-agency communication creating or reinforcing a silo mentality. Inefficiencies in integrated working—across both children's and adult's services and hospital and community services—are another recurring theme in the transition literature [32, 34–36]. When this service fragmentation is combined with inadequate information provision (another frequently highlighted system-level barrier), navigating the system becomes difficult [23, 32, 36, 37].

System-level barriers to effective transition relate to the culture, processes and resources in adults' services. These include lack of involvement in the planning process, lack of confidence in supporting adolescents as a distinct group and delay in initial appointments in adults' clinics [32, 37–39]. Even when AYASHCN are seen in adults' services, it can be that—for reasons of eligibility or lack of availability—they no longer

have access to the same specialist expertise as they did pre-transfer [32]. The reasons for these inconsistencies are numerous including, for example, different service eligibility thresholds, incoherent service priorities or rigid service protocols (which may include clinical indicators that need to be met pre-transfer [40]) impeding individualised care [32]. These are likely to be compounded by lack of both resources and training to address the particular needs of these young adults [23, 32, 40]. By contrast, on the pre-transfer side, reluctance of children's service practitioners to hand over the AYASHCN's care, particularly when relationships are well established, has been identified as a barrier to transition [32, 36, 41]. Related to this, delays or inefficiencies in making referrals to adults' services stymie the transition process [29, 36]. There is evidence from multiple countries (the U.S.A., Canada, U.K.) that young people are invariably not referred to a specific adults' services clinician or are transferred with poor, or no, information provided to adults' services about their conditions, preferences and needs [41].

Involvement of parents in the transition process can also be a barrier to effective transition. On one hand, parents can struggle to adjust to their child's burgeoning autonomy. This can stymie practitioner efforts to encourage young people to take increasing ownership of their care [41]. On the other hand, young people can feel frustration if there is either too much focus on parents' wishes (such that they are excluded from the process) or insufficient recognition of the support they still draw from their parents [32, 37] even though they will be required to take on more responsibility for their health as part of transition.

At the individual level, certain groups of adolescents are at particularly high risk of poor (or no) transition including those who are looked after by the state [27, 42, 43], experience mental ill health [26, 42], are disabled [44], have palliative care needs, or have complex, multiple needs [45]. Opportunities to spot AYASHCN most at risk of poor transition, and intervene early, are frequently missed [46]. AYASHCN with mental health needs and developmental disabilities,

among others, can face significant challenges in later life if their needs are not met during transition [31].

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## Overarching Good Practice Principles

A model of care can be defined as 'an integrated system of services that facilitate best practices of care' [16, p. 376]. Given that service transition takes place within the context of developmental transition and situational transition, a range of outcomes should be considered when evaluating whether any model works to deliver care in this way [14]. No single model can be identified confidently as the most successful [25, 32, 47–49]. This is attributable to a paucity of high-quality, robust research on effective approaches to transition. Many novel practice models are being developed, but this is often in isolation and/or without robustly designed evaluation of impact [50]. A number of emerging models have delivered positive impacts; examples are described later. In addition, looking across models, and in the wider literature, it is possible to identify some overarching success factors. The four key principles summarised in Table 28.1, and described thereafter, represent common features of effective approaches.

While the importance of empowering young people to make decisions about their care is beyond dispute, the extent and quality of genuine partnership work with young people varies hugely. Effective transition planning should always put the young person at the heart of all discussions and decisions about their care. This approach is both valued by AYASHCN and improves outcomes [32]. A young person-centered approach is one in which they are involved in service design, delivery and evaluation at both strategic and individual levels; the production, piloting and evaluation of transition-related materials and tools; and review of their own transition, to find out if they achieved what they wanted and needed to achieve. In working with AYASHCN in this way, practitioners should apply a strength-based philosophy. Care should

**Table 28.1** Principles of effective transition support

1. Young person centred	The young person is enabled to take part in all discussions and decisions about their care. Their needs and preferences are taken into account
2. Holistic and empowering	The young person is treated as more than just their condition. Care is offered in the context of their wider life, aspirations and circumstances. They are empowered to self-manage
3. Coordinated and planned early	Transition starts around the age of 13 or 14 (at the latest) and at a time the young person can cope with and engage in it. They have a single named worker to support them throughout the process
4. Consistent and jointly owned	Responsibility for transition is shared between children's and adults' services. Young people are tracked throughout the process to ensure post-transfer follow-up actually happens

be individually focused and flexible, founded on what the AYASHCN is able to do and wants to do, rather than how they are limited by their condition [16, 32, 38, 51].

Support should address more than the health condition alone. Effective health-care transition is provided in the broader context of what it can enable the AYASHCN to achieve in their day-to-day life [32, 47]. Focusing solely on managing the health condition, or presenting a predetermined set of treatment options, can limit both the quality and experience of transition. Practitioners should draw on AYASHCN's skills and abilities and the links they have with carers, family and friends. Using these resources to best effect can help to build AYASHCN's confidence and interest in and ability to self-manage their health conditions and coordinate their own care [32, 45, 50, 52]. A strength-focused approach of this type contrasts to 'the often reactive medical model of adult health care' [22, p. 435].

Multimodal approaches that use both web- and mobile-based technologies can empower AYASHCN to self-manage their health [53]. Offering peer support, coaching and mentoring

and advocacy can help AYASHCN play an active part in planning their own transition. All aspects of transition should take account of the young person's communication needs and preferences. A written record, in the form of a 'communication passport' or 'one-page profile' that the young person can share with others, can help make sure everyone providing support knows what is needed in this respect [54].

Good coordination and planning are central to any effective model of support. There is strong, consistent evidence about the benefits of a single practitioner to help AYASHCN navigate services; make the links between everyone involved in their care; provide, or tell people where they can find, advice; and arrange appointments and help young people to access them. This is a designated role rather than a job title, to be assumed by someone already providing support to the AYASHCN [54].

The timing of the transition planning relates to the difference between transition and transfer. Fictional case studies that involve timing and other aspects of HCT planning are presented in Table 28.2. Transition planning should start early, around the age of 13 or 14, and well before the physical transfer to adults' services [54]. Rather than imposing strict age thresholds, services should take account of each AYASHCN's development and the things happening in their life to make sure they are ready and able to deal with this change [41, 54]. Indeed, the importance of assessing transition readiness, as part of a coherent, comprehensive approach to transition planning, is a consistent theme in literature [14, 41]. This responds specifically to the need to recognise the range and nature of other priorities in the young person's life [39].

The number of AYASHCN lost to follow-up after transfer is a significant problem [14, 41]. To avoid transitional care being seen as someone else's responsibility [55, 56], it is critical that children's and adults' services share responsibility for pre- and post-transition support (to coordinate the actual transfer) (see Chaps. 9–12 and 16–18). In addition, it is important to track young people throughout the process to ensure post-transfer follow-up actually happens [14].

There should be systems and processes in place to prevent services losing contact with AYASHCN discharged from paediatric care. A good practice guideline in England specifies that AYASHCN should see the same health-care practitioner for the first two appointments post-transfer, and there should be proactive follow-up with those who do not attend appointments. In addition, at an early stage pre-transfer, they should be told about alternative sources of support in cases where there is no adults' service to which a young person can be referred [54].

### Effective Transition Approaches

A range of promising initiatives are being implemented with some emerging evidence of benefits. Broadly, these approaches can be classified as joint working, bridging services or youth-focused support [57]. This section includes a brief summary of each, with illustrative examples from

**Table 28.2** Fictional case studies: typical versus effective transition

Typical transfer transition	Effective transition, applying good practice principles
<p>An 18-year-old male, suffering from ADHD and a mood disorder needed transition from child to adult mental health care. Having received very good clinical care from child services, the treating team could find no adult providers willing to take over care. The young man was discharged to a community counselling service who deemed him 'too complex and risky'. He was therefore left without any provision, being too complex for available community services but not 'ill enough' to be treated by adult mental health service</p>	<p>At a routine appointment, a paediatric nurse talked to a 16-year-old female about future transition. This was in a relaxed way, without any pressure to make decisions about transfer. Soon after this, she introduced the patient to a nurse from the adult clinic. Gradually, the young woman started having appointments with the adults' services nurse, in the paediatric department. She was then invited to visit the adults' department, when she was ready. On her visit, the adults' service nurse showed her around the department and explained how things worked. When she was nearly 18, she decided herself she was ready for transfer</p>

practice alongside evidence of effectiveness and cost-effectiveness.

### Joint Working

The value of close, collaborative working between practitioners in adults' and children's services is well-evidenced [31, 34, 35, 45, 51, 58]. Shared responsibility for AYASHCN's care before and after transition is common to a number of emerging condition-specific transition models in the U.K., U.S.A., Canada and Europe (Belgium, Germany and the Netherlands) [50]. In practice, this means emphasising the importance of cross-agency collaboration at system level [16], and then translating this into strategic and operational policies, for example, by having a named responsible person at each of these levels, as well as a shared vision and jointly agreed processes and protocols [32, 35, 38, 52, 54].

Involving primary care services and staff in transition planning is emerging as an important clinical and research theme. Research from the UK, for example, indicated the importance of community-based general practitioner involvement in transition planning especially for young people with complex needs [29]. This is a best practice recommendation in the UK (England-specific) guidance [54] which may be transferable to other countries in which a similar practitioner role is a core component of community provision (such as Australia, New Zealand, Canada and much of Europe). Evidence about the detailed arrangements for primary care involvement is sparse, and, as yet, there is no definitive model of good practice in this area [48].

### Bridging Service

#### Support from Designated Professional

A bridging service can take the form of support from a designated professional who engages the AYASHCN and their family throughout the transition process. In doing so, this worker helps the person navigate services and make decisions and provides continued support for a period after the

physical handover of care. A transition coordinator of this type, who may be a professional with another job title fulfilling this role, features commonly in a number of approaches [41]. In the UK this has been recommended explicitly as good practice in national (England-specific) guidance [54]. It has been suggested that effective multi-agency integrated working can remove the need for a bridging coordinator [16]; however, it may be that an effective holistic approach includes both.

There is a small amount of evidence to highlight the potential value of nursing staff in the coordinator role, where transition takes place in community settings [59]. A recent Cochrane Review included an evaluation of a nurse-led approach to one-to-one transition support [60] and noted that this led to modest improvements in disease knowledge and self-management [49]. A retrospective U.S. cohort study of condition-specific (diabetes) outpatient clinic care found that having consistent support from the same allied health professional or clinician after transfer, as before, predicted lower hospitalisation rates [61].

### **Structured Transition Programme**

A retrospective cohort study of a structured transition programme in Italy identified clinical and service-level benefits when compared to data prior to implementation. The intervention included support from a transition coordinator 1 year prior to transfer and after the move to adult services. In addition, the adults' service clinician was involved in transition planning, and delivered the last children's clinic appointment, and the first in the adults' clinic, jointly with the paediatric consultant. The condition-specific outcome (mean HbA1c) improved and was sustained over a year post-transfer, and attendance was higher in the structured transition group [62].

### **Transitions Clinics**

A number of reviews have considered the effectiveness of transition clinics. The difference in the composition of these models, and the lack of rigorous trial evaluation data, renders it difficult to draw firm conclusions about clinical and cost-effectiveness [50]. There is some evidence that the components of these interventions offer the poten-

tial to improve both condition-specific outcomes [45] and the experiences of AYASHCN and their families [31] and it is possible to identify such shared features. Common to a number of condition-specific (rheumatology) transition clinics across the U.S.A., U.K., Canada and Europe, for example, are models comprising a written transition policy (with input from both children's and adults' services); shared responsibility for care before and after transfer, supported by communication of relevant information; flexible, personalised, early transition planning; a transition coordinator; and empowerment of AYASHCN through education and information [50].

One condition-specific model (renal transplant) from Canada comprises a multidisciplinary team including a social worker, support and education using email and mobile technology, regular (4–6 monthly) appointments pre-transfer at time points agreed to suit the needs of the AYASHCN, and comprehensive handover communications and 'matching' of AYASHCN to adult clinicians best suited to their needs. A retrospective cohort study attributed a number of benefits to this model including improved clinical outcomes (no death or graft loss) and, as a result, a cost saving [63].

## **Youth-Specific Models**

### **Young Adult Team**

A retrospective cohort study conducted in the UK found that AYASHCN supported via a dedicated multi-agency Young Adult Team experienced improved function and societal participation, compared to those who did not have access to this service [64]. This was supported by economic evidence that indicated the outcomes were not associated with increased cost.

### **Training Courses for Young People**

A range of interventions focus on supporting AYASHCN to either increase their ability to self-manage or to engage more directly in transition planning; and this has taken different forms. A randomised controlled trial of a training course to help young people develop their health-care

plan, included in a recent Cochrane Review of health-care models [49], found no evidence of impact on self-efficacy, quality of life or condition management [30]. A recent integrative review, however, highlighted that self-management training is a common feature of transition support activity across the UK, Canada and Europe and noted that empowering young people to take ownership of their health is a success factor for transition [41]. This was supported by a review of mental health-specific models [16].

## Gaps in the Research

The most significant gap in the research is the lack of robust effectiveness evidence. High-quality comparative and longitudinal studies are needed to understand what works, for whom, under different circumstances (see Chap. 13). Research should also seek to understand cost-effectiveness, alongside effectiveness, and the length of time over which impacts are realised and sustained. An agreed definition of successful transition outcomes is also lacking.

There is a pressing need to provide support to practitioners working with young people on both sides of the transition divide. More research is needed on the most effective approaches to and impact of transition training for practitioners.

In summary, transition from paediatric to adult-based care is a problem shared by health-care systems across many countries, and future research on evidence-based approaches will likely benefit AYASHCN across international boundaries.

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