

# Transition from pediatric to adult services: are we getting it right?

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## Purpose of review

The transition of healthcare from pediatric to adult settings has become more significant over the past 20 years as the survival of young people with chronic illness and disability has increased and healthcare delivery has become more complex. This review examines the evidence from recent studies and position statements to determine the current issues relating to transition.

## Recent findings

Although there are many examples of excellent transition processes, these are mostly confined to individual clinics (often subspecialist), with little evidence of hospital-wide or regional planning. The notion of transition to adult healthcare has now spread from its roots in adolescent medicine to influence many subspecialty areas of practice. However, it remains largely confined to a pediatric paradigm and risks becoming disconnected from the principles and practice of adolescent medicine from which it emerged.

## Summary

More systematic investment in regional clinical service planning is indicated, as is investment in more systematic approaches to training both pediatric and adult healthcare providers around the importance of transition to adult healthcare. Collaboration is urged in relationship to clinical service developments, training and research initiatives.

## Keywords

adolescence, adolescent medicine, chronic illness, self-management, transition

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## Introduction

In young people with chronic illness, the importance of transition from pediatric to adult healthcare settings has been formally recognized for at least a decade, with policy statements dating back to the early 1990s [1]. Since then, the reach of policies and guidelines has extended from adolescent societies such as the Society for Adolescent Medicine [2] to pediatric societies [3,4<sup>\*</sup>], with more recent publications by adult medicine societies [5] and disease-specific and discipline-based groups [6,7]. Much has been written about the importance of transition [8<sup>\*</sup>,9–13] and gradually more research has been conducted [14–18]. However, questions remain as to whether the actual transition process has improved for the majority of young people with chronic health conditions, about what impact transfer to adult healthcare has on young people's health and developmental outcomes and about how more systematic approaches to improving clinical services for young people with chronic conditions can be developed.

Pharmacological, surgical and technological advances have resulted in many children now surviving through

adolescence and into adult life with conditions that were previously fatal in childhood [19,20]. Indeed, relatively large cohorts of older adolescents requiring complex multidisciplinary care are now regularly transferred to adult services. For example, as the average life expectancy for people born with cystic fibrosis since 1990 is now expected to be 40 years [21], the need for specialist adult services has become largely self-evident in this field. However, the transition path continues to be rocky for many young people. On one hand, problems arise because adult specialist services do not provide the same level of comprehensive and developmentally appropriate clinical care as provided by pediatric services for young people with particular physical health concerns (e.g., metabolic disorders), let alone for young people with intellectual disability or mental health disorders. On the other hand, problems continue to arise because of the lack of attention by pediatricians to preparing adolescents to transfer to adult services. For example, in a US population-based study of parents of 5533 young people aged 13–17 years with special healthcare needs, only 50% reported their child's doctor had talked about changing needs in adulthood, of whom only 59% (or 29% of the total sample) reported having developed a plan to address

these needs, and only 42% (21% of the total sample) had discussed shifting their child's care to an adult provider [22].

Why is the transfer of healthcare so important? At worst, if it is not handled well, particularly in those with more severe chronic illnesses, failure to engage with adult services makes routine clinic attendance less likely. This risks disrupting young people's emerging capacity for self-management, which threatens adherence to treatment and, ultimately, health outcomes [18]. More broadly, however, the growing appreciation of poorer developmental outcomes in young people with chronic disease [23] challenges pediatric and adult providers to consider anew how further gains in mortality and morbidity are not at the expense of developmental outcomes.

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### Transition and transfer

Typically, the term transition describes the period of preparation prior to and after the event of transfer, which describes the actual shift from pediatric to adult healthcare including transfer of health information. Most guidelines discuss the importance of careful planning and discussion with patients and their families about the likely timing of transfer to adult healthcare services, although there is no consensus about when these discussions should first be held. Depending on the patient's age and diagnosis, it may well be appropriate to include discussion of transition as early as the first appointment. Far less is known about the process of transition that continues after the event of transfer, as most evaluation studies have focused on the first 12 months or so after transfer [14,15]. Having an agreed transfer date helps to reduce confusion about the expected process for the patient, family and healthcare teams. It also confirms clear lines of responsibility for the treating clinical teams, with the adult team taking on the responsibility for the patient once their healthcare has been transferred.

Most of the transition literature is based on descriptions of relatively small cohorts of patients with single disorders (e.g., cystic fibrosis, spina bifida) or similar groups of diseases (e.g., rheumatological), generally from single institutions. Much has been learnt from these approaches, which has no doubt influenced the development of disease-specific or discipline-based transition policies [24]. However, the field would benefit from studies of larger cohorts of young people with single conditions and from studies of larger cohorts of young people with different chronic conditions in order to understand both the similarities and the different needs as they mature of young people and families with different groups of conditions, such as physical illness, physical disability, intellectual disability and mental disorder.

The content of many transition policies and guidelines has included topics such as the skill set required by young people to negotiate the adult healthcare system as well as many systemic issues needing to be addressed, such as training for healthcare professionals and ensuring adequate transfer of health information, to name just two [2,3]. There has been a similar focus on appreciating that the complexity of transition to adult healthcare for many young people requires different healthcare professionals working together in order to get it right [25]. Indeed, determined individuals who appreciated the lack of access to future adult healthcare for their patients and who developed good relationships between themselves and adult colleagues were largely responsible for the success of most early transition models and adult service developments. Increasingly, however, the complexity of contemporary healthcare means that more systematic approaches to the development of adult services and to how to best support the necessary linkages between pediatric and adult services are required. Many parts of the world would benefit from regional health planning to identify appropriate transfer paths (e.g., adult services). Similarly, many hospitals would benefit from transition policies to prioritize the development of the support services required to facilitate linkages between pediatric and adult services [26].

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### Chronic illness management

Transition to adult healthcare is part of the developmental process for young people with chronic diseases and disabilities. Prior to consideration of the transition process itself, it is worth considering the wider management of adolescents with chronic diseases, as this is the bedrock on which successful transition is based. Preparation for transition can begin early for children and their families attending pediatric services by simply mentioning that transfer to adult services will occur one day. In this vein, the concept of future transfer to adult services can be normalized by comparing healthcare transfer with other developmentally normal transitions, such as the move from primary school to secondary school.

However, preparing patients involves more than simply describing future events and raising awareness of their ultimate transfer to adult healthcare (whether within primary care or specialist settings). Adult health services assume that patients have a high degree of autonomy and knowledge about their health and its management, and that they have the capacity to independently negotiate the healthcare system. The expectation of self-management involves a focus on the individual and his or her capacities, rather than the family [27]. Pediatric care conversely assumes that children are not autonomous or knowledgeable about their health and its management, with clinicians focusing as much if not more on parents or

carers or both than on children. Within the pediatric setting, a gradual shift from parent-managed to self-managed care is required if young people are to function relatively independently within adult healthcare settings [28].

Application of the principles of adolescent medicine can assist young people and families to develop many of the skills that are ultimately required to negotiate the adult healthcare setting confidently and safely. These same principles also allow parents and doctors to 'let go' by encouraging young people to develop relative independence in healthcare as well as in other aspects of their lives.

An appreciation of the gradual process of maturation and skill building that promotes future self-management and the capacity to engage with the adult healthcare system is clearly needed for all health professionals managing patients with the 'traditional' chronic diseases that are typically managed within tertiary pediatric hospital settings. Attention to these developmental concepts is also required when managing young people with other complex disorders, who are more commonly managed in the community, such as young people with intellectual disability or attention-deficit/hyperactivity disorder (ADHD) [29]. However, in the absence of the high cost of inpatient care that is often the driver of new health service developments [30], creating sufficient impetus for adult clinical service development within outpatient or community settings can be more challenging.

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### **Principles of adolescent medicine practice**

In the USA, adolescent medicine has been recognized as a legitimate area of medical practice for 40 years, with the establishment of the Society for Adolescent Medicine in 1968 [31]. Specialist adolescent medicine services have long been a feature of other resource-rich countries such as Canada and Australia, while a number of other countries, both resource-rich and resource-poor countries, such as Hong Kong, Singapore, Malaysia and Vietnam, have more recently started developing clinical services for adolescents.

The principles of adolescent healthcare are based on a biopsychosocial approach to clinical interactions. An appreciation of normal adolescent development is pivotal to developing a clinical approach that allows engagement with teenagers by establishing trust and rapport. With the aim of providing accessible and developmentally appropriate healthcare, the key clinical skills taught within adolescent medicine curricula include the provision of confidential healthcare and routine psychosocial assessment, both of which require health professionals to see young people alone for at least part of the health con-

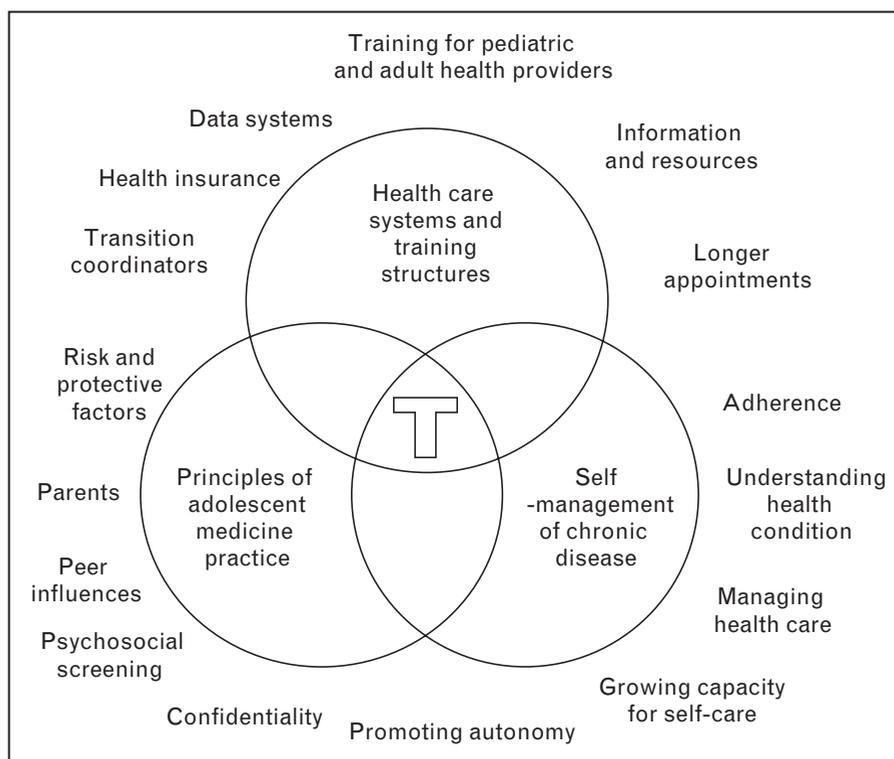
sultation [32]. Health risk screening, such as the HEADSS framework [33], is as important in adolescents with chronic illness as in other young people. Not only are adolescents with chronic disease more likely to have poor mental health, but also there is increasing evidence that this population is just as likely – if not more likely – to engage in health risk behaviors than otherwise healthy young people [34]. Furthermore, these young people are 'doubly disadvantaged' as the risks from participating in these behaviors (e.g., smoking, substance use) are commonly greater than experienced by their healthy peers [28,34].

When managing young people with chronic disease, the core clinical skills of adolescent medicine can be used to promote a growing capacity for self-management. Indeed, when early discussion of transfer to adult healthcare is combined with the principles of adolescent medicine, it is highly likely that patients and their families will be well prepared whenever they are required to transfer to adult services. Transition checklists have been developed to describe the readiness (or otherwise) of young people for transfer to adult services [35]. Questions commonly address issues of autonomy and independence with healthcare that would equally fall within the rubric of self-management or, indeed, within the knowledge, skills and attitudes that are embodied in the principles and practice of adolescent medicine.

Within discipline-focused or disease-based groups, discussion about transition to adult healthcare risks takes place without reference to the underlying principles of the practice of adolescent medicine from which the concept emerged. There is, however, remarkably extensive overlapping of these concepts, especially when young people's perspectives are taken into account [36]. Discussion of self-management in young people with chronic disease, a notion that has emerged from the adult healthcare sector, similarly risks being disconnected from the principles and practice of adolescent medicine that are central to the delivery of quality healthcare to adolescents with chronic disease.

What deserves equal emphasis is the need for effective clinical systems that support the provision of appropriate healthcare for adolescents with chronic conditions, including transition to adult healthcare. This requires specific information and resources including hospital-based transition coordinators and appropriate training for staff working within both pediatric and adult services. In Fig. 1, we have illustrated how transition to adult healthcare can be conceptualized as an area of overlapping knowledge, skills and resources embodied within different aspects of health practice and the service system.

**Figure 1** A schematic representation that shows transition to adult healthcare placed at the intersection of the overlapping knowledge, skill sets and resources that constitute the principles of adolescent medicine, self-management of chronic disease and healthcare systems and training structures



T, transition.

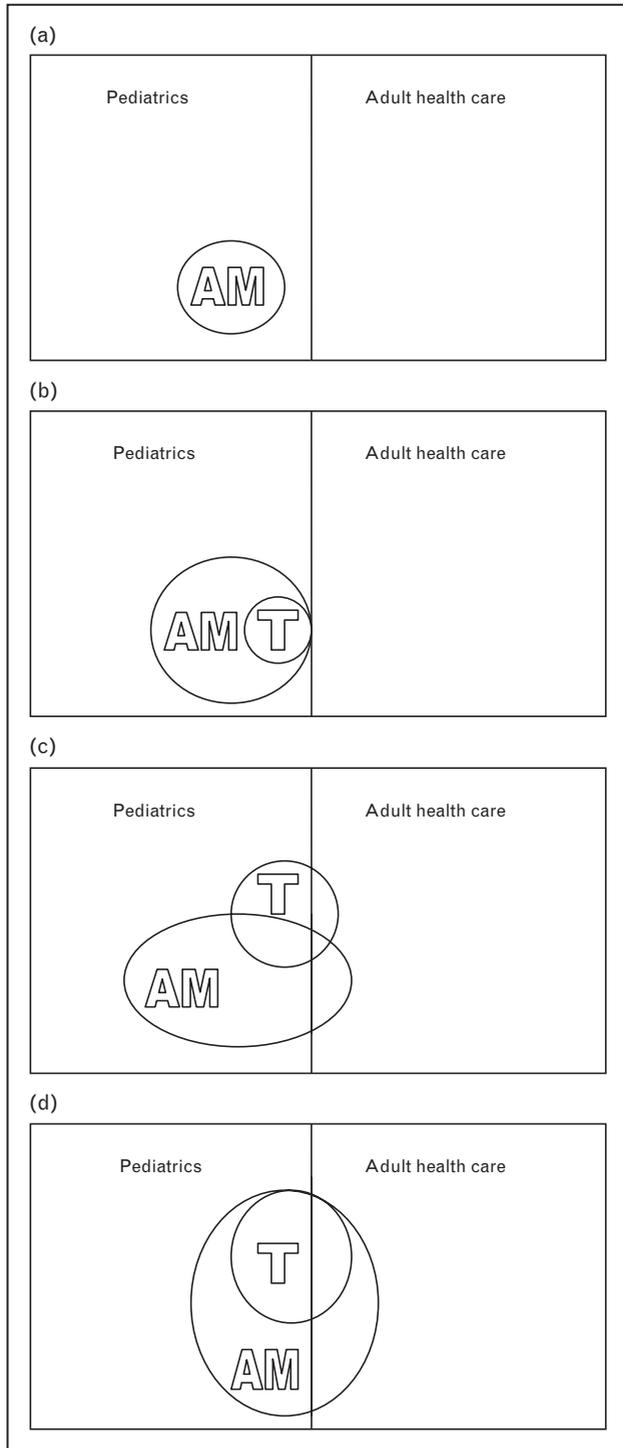
**Getting it right**

Over the last few decades, adolescent medicine largely emerged from the discipline of pediatrics to become the multidisciplinary subspecialty we know today (see Fig. 2a). Early leaders within adolescent medicine provided leadership, primarily within pediatrics, about the newly defined notion of transition to adult healthcare and how important it was that young people with complex, chronic or disabling conditions were able to have their healthcare transferred from pediatric to adult health settings (see Fig. 2b). Although the concept of transition to adult healthcare has been recognized as important by children’s hospitals and services, it has largely remained within the pediatric paradigm. As described previously, the responsibility for ‘getting it right’ too often seems to reside within individuals, individual clinics and departments, with less investment in hospital-wide or regional planning that is required to support more strategic clinical developments, including an appropriate training agenda. In most parts of the world, there has been a failure to influence system-level changes within pediatrics that would appropriately support transition to adult healthcare.

Figure 2c describes the relative growth of the discipline of adolescent medicine within pediatrics with gradual extension into the adult sphere. Increasingly, it is appreciated that the principles of adolescent medicine should be practiced by all physicians who work with young people, whether in primary or specialist healthcare. In some parts of the world, the value of developing training pathways and clinical or academic roles or both for specialist adolescent medicine providers is also being recognized.

Figure 2c also depicts the growing recognition of the importance of transition to adult healthcare and the differentiation of the concept of transition from more basic principles of adolescent healthcare. This has been largely achieved by the successful promulgation of the notion of transition to adult healthcare by individuals working within specialist pediatric medicine, such as rheumatology, cardiology and oncology. For transition pathways to be as smooth as patients and families should expect them to be, appreciation of the multiple principles, people and processes that support transition to adult healthcare needs to become strongly embedded

**Figure 2** Diagrammatic representation of the emerging and growing awareness of both the principles of adolescent medicine and transition to adult healthcare within the practice of both pediatric and adult medicines



AM, adolescent medicine; T, transition.

within both pediatric and adult service models and funding frameworks, as outlined in Fig. 2d. Rather than differentiation and fragmentation, greater appreciation

of how the different knowledge, skills and resources that, when combined, result in successful transition to adult healthcare is recommended, with a stronger focus on the principles of adolescent medicine.

Governments, health insurers and hospital administrators need to acknowledge the importance of both the principles of adolescent medicine and transition to adult healthcare not only in terms of the potential benefits to patients and families from increasing satisfaction with care and decreasing morbidity, but also in terms of the cost savings when we 'get it right'. Although some areas of clinical practice are now well advanced in terms of this conceptual and service development framework (e.g., specialist cystic fibrosis services), other areas of practice are less well developed. Similarly, while transition to adult healthcare is more firmly on pediatricians' minds than previously in most resource-rich countries, the same cannot be said for our adult colleagues, whether in specialist medicine, gynecology or psychiatry. And, consistent with the lack of adolescent medicine services in many parts of the world, appreciation of the very notion of transition to adult healthcare (and the principles of adolescent medicine) is still at an early stage in some countries.

Within outpatient clinics, consulting with the young person alone without their accompanying parents is an important step towards building autonomy in healthcare, as is time spent with the young person and parent together. However, this style of adolescent consultation is not possible without tacit support from health administrators to book longer consultations for adolescents. Similarly, appointment letters should be addressed to the young person when appropriate, rather than defaulting automatically to the parents, a problem recently encountered in our institution. Within inpatient environments, an important aspect of the physical environment is to group young people together on adolescent wards [37]. In addition to encouraging increased autonomy and independence in healthcare, these environments provide valuable training for medical and nursing staff as the principles of adolescent healthcare are put into practice with every patient. Importantly, young people prefer them to the alternative of being nursed with younger children or older adults, and they have been shown to be associated with improved quality of care [38].

However, prioritizing developmentally focused rather than disease-focused health services can be challenging for physicians and health administrators alike. In Australian children's hospitals, adolescent wards have been a feature of specialist children's hospitals for over 2 decades. More recently in the UK, adolescent and young adult cancer services have successfully argued for separate physical services on the grounds that a developmental

focus will improve both health and well-being [7], a model that is now being emulated in other parts of the world [39].

Regardless of the stage of clinical service developments, studies consistently suggest a need for knowledge and skills about the principles of adolescent medicine as well as transition to adult healthcare to become more firmly incorporated into teaching and training programs for healthcare professionals [40,41]. This applies as much to nursing and other multidisciplinary health trainees as it does to medical trainees. In many parts of the world, adolescent medicine has increasingly become incorporated within the undergraduate medical curriculum [42], though it is less consistently taught within nursing and other multidisciplinary health courses. A stronger focus is equally required in postgraduate training. In Australia, a new training resource for adolescent health (which includes sections on promoting self-management of adolescents with chronic illness and transition to adult healthcare) has recently been developed for postgraduate specialist physicians in training [43]. Importantly, this resource will be distributed not only to pediatric trainees, but to all adult medicine trainees as well.

The rise of the consumer movement and greater access to electronic information are but some explanations for why young people and their families are developing higher expectations about healthcare delivery. Good transition planning will be increasingly expected by this population. The extent of deficiencies in clinical services in many parts of the world suggests that, rather than relying on passionate and committed clinical leaders in pediatrics to generate incremental service developments as has occurred to date, more widespread changes are required. The UK provides a good example where, in relation to both rheumatology and cancer services for adolescents, a much stronger focus is emerging about getting health services right for young people. If successful, the challenge will then be how to extend these early developments beyond single disciplines and conditions more widely to adolescents with chronic or disabling conditions.

## Conclusion

Getting transition right must be underpinned by successful and sustained collaborations across pediatric and adult health services. McDonagh *et al.* [24,40] have rightly called for closer collaboration between specialist medical providers and adolescent physicians in relation to training in adolescent medicine. Britto [25] has similarly called for greater collaboration between specialist providers and adolescent physicians in order to ensure developmentally appropriate clinical services for adolescents with chronic disease. Collaboration must involve both pediatric and

adult providers with emerging evidence that health outcomes are not compromised by transfer to adult services when the service system does 'get it right' [44]. Greater collaboration with researchers would equally see the development of a stronger evidence base from which clinicians could advocate with health administrators and governments for more strategic investments in clinical service development and training. Finally, collaboration with consumers through careful harnessing of the dissatisfaction and frustration of young people and their families as they negotiate the all too rocky – or even absent – path from pediatric to adult services is recommended as the most likely way of getting more immediate action.

## References and recommended reading

Papers of particular interest, published within the annual period of review, have been highlighted as:

- of special interest
- of outstanding interest

Additional references related to this topic can also be found in the Current World Literature section in this issue (p. 495).

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