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Developmentally Appropriate Adolescent Health Care: An Essential Prerequisite for Positive Transition Experiences

Deborah Christie and Gail Dovey-Pearce

Introduction

As a direct result of improvements in medical care, therapy regimens, and advances in medical technology the number of young people with chronic illness and/or disabilities surviving into adulthood is increasing [1, 2].

The organizational boundary between children's and adult services remains the starting point for many clinicians, managers and researchers focusing on structural boundaries and the changing landscape associated with adult services. There is a common assumption that transition should start around 16. For example, in the UK National Service Framework for children, young people and maternity services the emphasis is for pediatric services to retain responsibility for young people until their 16th birthday, if not till 18 years [3].

The majority of current transitional care models are located within disease specific specialist teams based in hospital-based clinics [4]. Professional guidelines from the UK [5–8], USA [9], Canada [10], and the World Health Organization [11] address the need for transition in adolescence and adolescent health and

D. Christie (✉)
Department of Child and Adolescent Psychological Services,
University College London Hospital NHS Foundation Trust,
London, UK
e-mail: Deborah.christie@uclh.nhs.uk

G. Dovey-Pearce
Department of Child Health (c/o Health Psychology, DRC),
North Tyneside General Hospital, Northumbria Healthcare NHS Foundation Trust,
North Shields, UK
e-mail: gail.dovey-pearce@nhct.nhs.uk

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propose parameters for what transition programs could and should look like. The UK Department of Health published guidance that is freely available on the internet [12], whilst McDonagh [13] reviewed 232 papers summarizing the literature and producing a toolkit to enable the planning and implementation of transition services.

However, this traditional focus on 'healthcare transition', as the 2–3 years around the move between child and adult services, offers a limited and unhelpful perspective. It is essential to see transition as a key component of overarching, developmentally appropriate healthcare (DAH) for adolescents and young adults. DAH requires an approach by healthcare professionals who understand and respond to the changing biopsychosocial and developmental needs of young people, embedding individualized healthcare, health education and health promotion, by engaging effectively with each young person and their carers [14].

Within the literature and chapters of this volume, DAH is closely linked to the concept of transition and in providing DAH, transition and transfer will be addressed as these needs arise.

> …if we had true age and developmentally appropriate adolescent health services, incorporating all facets of adolescent health, transition would flow naturally. As this is not yet the case, it is important to understand concurrent adolescent developmental issues in conjunction with chronic health issues [15].

DAH is the "key principle underpinning the practice of adolescent medicine" [16] supporting the care of young people from early adolescence through to young adulthood, with transition and transfer as distinct aspects of this more broad conceptualization and process. Whilst there will be some specific needs—related to diagnosis and treatment—in order to better understand, define and operationalize DAH, researchers and clinicians must consider the existing and emerging evidence about adolescent development, looking to fields such as psychology, sociology and neurobiology.

Within the field of developmental psychology, for example, "emerging adulthood" has been described as a developmental phase in Western societies between late teens and early 20s. It is characterized by feelings of ambiguity and experimentation as young people strive towards abstract goals, such as responsibility and independence. Concrete markers that once delineated adulthood such as marriage and childbirth, now tend to happen later in life. Within neurobiology, new evidence relating to the development of brain areas associated with social behaviors might support openness to social stimulation and the importance of peer acceptance as key components if young people are to "strike out" from their family of origin. This evidence may also underpin risk-taking and reward-seeking behaviors that can enable adolescents to try different experiences and explore the costs and consequences; necessary for their development of self-determination and identity. Such theories help to contextualize young people's thoughts about illness, well-being and self-care behaviors as much as other cognitive and behavioral domains. Experimentation and oscillation in social behavior is also observed in patterns of self-care. The ambiguity for young people around what marks the boundary between childhood to adulthood is mirrored by a perception of one's self as a young, vital being balanced against the challenges of a long-term health condition more in keeping with "old age." The importance of peers and social referencing has been explored as a useful intervention for health teams (e.g., peer mentoring) but also means that young people often wish their condition 'away' in their desire to be "normal."

Adolescence through into young adulthood is, therefore, a unique and critical period of development when specific prevention and intervention strategies may still alter trajectories and decrease threats to health along the adult life course. However, unmet health needs and disparities in access to appropriate care, health status and mortality rates are high. Young adults between 18 and 25 years of age experience higher rates of mortality and unplanned pregnancy, and lower access to health care compared to those immediately younger (10–17 years of age) and those immediately older (26–30 years of age). As the disparate health status and the biological development has become known, young adulthood is increasingly seen by international and United States adolescent and young adult health researchers as a vulnerable developmental period, and therefore, in need of specific focus and attention [17, 18]. The change of emphasis in relation to health condition focuses on greater resilience, self-care, integrated support from services and embedded social support [17, 19]. These factors mean that the time when young adults move away from their parental home to independent living can be fraught with challenges. Evidence suggests that those young adults that do the worst are those who have not had attention paid to the complex balancing act between medication demands, hospital appointments, work and social activities, nutrition and key tasks of development [18]. This chapter provides an overview of the better evidenced approaches and interventions within "adolescent medicine," including some specific to the process of transition. These approaches include how to think about and assess whether a young person is ready to cope with the multiple and changing healthcare challenges as they move from adolescence to adulthood.

Approaches and Interventions to Support the Provision of DAH

There remains a lack of evidence for 'what works' in adolescent medicine, DAH and transition, which continues to create a challenge for those tasked with putting policy into practice. Despite the constant flow of reviews, articles and commentaries on transition, in the last decade, the body of evidence describing service development has not grown at anything like the same rate as the number of young people who are now 10 years older and ready to transfer to adult services. It is suggested that the field remains constrained by a reliance on descriptive rather than evaluative studies and poor research design. A key weakness is the continued focus on a 2–3-year window around transfer and the lack of debate about what constitutes successful, long-term outcomes for young people managing their health condition in the context of their daily life.

A recent 5-year, UK study of health service provision and healthcare outcomes for young people aged 14–18, with LTHCs attempted to address some of these research design issues [20–22]. The authors concluded that 'healthcare providers working with YP should understand their individual needs and coping strategies allowing a personalized approach to their clinical care.'

In looking to provide such a person-centred approach, they found initial evidence to support a focus on three aspects of service provision for young people:

- promoting the young person's confidence in their ability to manage their health and wellbeing,
- supporting appropriate parental involvement (i.e., that meets the needs of both the parent and the YP), and;
- facilitating a meeting with the adult team before the transfer between services.

Developing Confidence in Self-Management and Healthcare Self-Efficacy

The development of self-management skills is associated with positive medical outcomes e.g. metabolic control, self-efficacy, and quality of life is improved in adolescents with diabetes taking part in self-management, education and coping skills training programs [23–26]. A key component of self-management is to ensure that young people have

(a) an awareness and knowledge of their medical condition
(b) an understanding of the rationale behind the recommended therapeutic regimen and
(c) consequences of selecting to follow a regimen of their own choosing.

Perceived self-efficacy rests upon the beliefs that a person has about their ability to manage the impacts of the events affecting their lives. It shifts and changes over the course of life, and is influenced by personal experience of managing events, seeing (at close hand) others coping with tasks, encouragement from peers and others in their social network and the awareness of internal responses (such as emotions) that can reinforce a sense of achievement or highlight potential vulnerabilities [27].

In order to help young people develop self-efficacy in relation to their health and wellbeing, the working relationship between the HCP and the YP is key. YP want their HCP to be interested in them as a person and not just in their medical need(s) above all, they must be perceived as approachable and trustworthy by the YP [28]. With such a rapport in place, the HCP is then in a position to be one of the people helping the YP develop the knowledge and skills they need to self-manage their care. This will include being able to identify signs and symptoms of emotional or physical health need, in addition—developing their confidence (in their own ability) to manage those needs—i.e., their healthcare self-efficacy. As part of this the YP will come to understand their own coping skills and strengths. Permission and partnership will allow a YP to have some trial-and-error experiences, knowing that they are able to ask for support when required. The HCP needs to consider that a YP will have competing priorities, such as academic and social pressures—this will help to contextualize the YPs decisions and responses, including the ones that are seemingly at odds with optimal self-care.

The HCP is only one person that the YP draws upon for support. Family members are the most central source of support and advice, including for health issues; peers also feature strongly in an adolescent's network [29].

Appropriate Parental Involvement

An earlier study found that one in three health professionals identified parental difficulties during transition, with successful transition influenced by parental and family factors [30]. Taking a step backward and encouraging independence is a challenge for many parents of adolescents that is made much more challenging by chronic illness and/or disability. This is certainly a view held by many adolescents. In a survey, 44% of adolescents with sickle cell disease stated that transition programs should offer "ways to help parents let their adolescents grow up!" [31].

A DAH approach would require HCPs to steadily encourage young people to take time and develop the skills to take an active part in consultations, independently of their parents. This will include practices such as: speaking directly to adolescents during the consultation, ensuring that their questions are ascertained, as well as those of the parents; having a small amount of time alone with younger adolescents, with this time increasing as they get older and more confident; and staff having the confidence to talk to young people about issues of increasing relevance, such as managing risks of experimental behaviors, exploring relationships and sexuality, discussing social media pressures etc. HCPS need to have the confidence to do this and may require support and training. They will need to have an awareness of other available services locally, to be able to signpost a YP to. The healthcare team cannot be specialist in their medical area and know all about issues of housing, sexuality, or education, for example, but will need to know who to contact or where information can be found. As well as individual HCPs having skills, information and confidence, managerial and organizational factors can also support the delivery of DAH, with practices such as offering all YP the opportunity to be seen alone usefully becoming part of the cultural norm within whole teams or departments, rather than being viewed as specialist practice. The parameters around confidentiality and consent need to be clearly understood by staff and explained to families, so that YP and parents can feel reassured about this steady change in emphasis and practice. Sometimes, young people will need support and encouragement to manage this shift and sometimes the parents will need to be reassured. This approach does not mean that parents are excluded from their young person's care. Some 15-year-olds will come to their consultations alone and some 21-year-olds will want their parent with them, even when transferred to adult services—healthcare teams need to create an individualized feel to care that makes either situation feel right for a patient.

Meeting the Adult Team

For those YP moving from child to adult services, the Paediatric health care teams are ideally placed to introduce ideas of independence and confidence. This will be best achieved by not asking how a single transition point should be managed but how best to meet the needs of the young person at each stage of development. Young people who have close working relationships with team(s) have less anxiety about the move to adult services, increased perception of improved coping and as a result they need less formalized support. As part of the transition process the team should enable the development of self-management skills which should parallel the psychological, emotional and cognitive development of the young person. The team should also take into account the family and social situation [32].

Even if the team completely changes when pediatric and adult services are culturally aligned, families can still experience a smoother and manageable transfer. Joint working and structural integration alone do not guarantee this alignment and it has been reported that clinical leadership and a commitment to adolescent health appear to be the additional active ingredients in services exhibiting highest levels of cultural continuity. Enabling families to manage the move and negotiate the cultural differences between teams is also central [33].

Having a Key Worker

Liaison personnel in both pediatric and adult teams, one of whom could usefully be a key worker/named worker throughout transition, should be identified for each individual and remain available to the YP until transition is successfully completed [34]. This kind of service development will have resource implications in terms of clinic space and/or time in addition to staffing levels, particularly for those practitioners not working within a multidisciplinary team. There is a requirement for multi-disciplinary and/or multi agency involvement especially for complex cases and teams.

Clinical Tools to Support the Provision of DAH

Young people are clear that they don't wake up one day feeling "ready" and even if they did, they may well change their mind the next day. Assessment of 'readiness' is not a unitary construct but rather requires an ongoing process over time. A recent systematic review [35] reported on ten tools specifically designed to "assess readiness." Seven were disease specific and three generic. Only the TRAQ (Transition Readiness Assessment Questionnaire) demonstrated adequate content and construct validity as well as internal consistency. The TRAQ is only designed to assess the concept of self-management and self-efficacy as described above and does not address the role of parental involvement or the development of a relationship with the adult team and its members. The authors would argue, strongly, that completing this as a one-off exercise at a predetermined age can only provide 'snapshot' view and thus violates good adolescent health principles. Questions about self-management and efficacy must be explored on a regular basis—and at the very least yearly from the point at which the young person starts to see themselves or be seen by others as a young adolescent.

Health Passports

There is enthusiasm for young people to be provided with a health planner (often described as a health passport) to record medications, treatments, school, activities and healthcare appointments, which serves as a portable and accessible health summary for the young person to take with them when they meet new teams. A relatively recent study of 50 young people found that young people said their 'health passport' was "helpful", especially with planning and organizing their healthcare [36]. However, they did not use it all of the time. The most frequent use was just before and after their move to the adult service. A combination of being busy in other areas of life and feeling that the HP was too big, meant that people thought it was hard work and didn't always use it. Young people seemed to use the HP in short but useful bursts and only used the sections relevant to them. Support to use it was key: e.g. help filling it in; the doctor asking to see it in clinic. Overall, young people showed a 'modest use' of the HP and to be useful it needs to be built into the consultation with the doctor rather than it just being left to the young person to complete. This is mirrored by the young people's work within the Transition research in the UK [37]. In a small-scale, exploratory survey, they elicited the views YP who had co-developed health passports for use within their service. Even having co-designed these tools, the YP said that they were "sometimes" useful but that they rarely remembered to take them to clinic, and that maybe the HCP and parents had more use for them. The emerging published findings and anecdotal evidence suggest that a wider investigation of the use and utility of hand held health records for YP is needed.

The Department of Health's "You're Welcome" self-assessment framework is another useful resource for all health services looking to be acceptable and accessible to young people [38].

There also standardized screening tools such as HEADSS [39] or the more current SSHADESS, which emphasizes strengths [40, 41]:

The SSHADESS Screen

- **S**trength
- **S**chool
- **H**ome
- **A**ctivities
- **D**rug/substance use
- **E**motions/eating/depression
- **S**uicidality
- **S**afety

Psychosocial Interventions

There is also limited evidence relating to the positive effects of psychosocial interventions designed to support transition. Data suggest benefit is only sustained for as long as interventions are provided and that the small number of studies, carried out in a number of different countries, make it difficult to ascertain the general applicability of any findings. Another challenge is that, to date, studies focus on narrow health outcomes rather than outcomes reflecting a holistic definition of transition, or (importantly) outcomes defined by young people. What an adolescent defines as a 'health outcome' may bear no relation to the outcomes defined by health care professionals.

More comprehensive and conceptually clear research is required. Also needed is a focus on the organizational and commissioning approaches that are central in underpinning long-term improvements within the field.

The Importance of Organizational and Commissioning Structures to Support Clinical Work

In a scoping review of studies reporting 'transition interventions', current evidence for practice was evaluated alongside how these practices become embedded within healthcare systems. Normalization Process Theory (NPT) is an evidence-based theory approach to evaluating how complex healthcare interventions become part of routine practice (i.e. normalized). Original studies were evaluated as to how far they showed consideration of four elements of NPT: (1) coherence (is the service perceived as valuable by service users and useful by the providers?); (2) cognitive participation (do staff think the work is a legitimate part of their role and do they support it over time?); (3) collective action (how does the work get done in the clinical context?); and (4) reflexive monitoring (how is the work formally evaluated and informally reflected upon). Most studies gave descriptions of interventions they were evaluating but reported little information about these aspects of service sustainability. Studies gave some account of the perceived value of interventions but there was little description of how staff incorporated the work into their existing roles. The focus was on individual champions and coordinators, with clear risks around sustainability and equity of provision.

The Colver et al. study [20] also concluded that there are important organizational and commissioning approaches that are required, to underpin the fundamental, clinical work. In terms of commissioning structures, YP's healthcare provision should involve fundholders (e.g., insurers or health commissioners (UK) of both child and adult services and that they should be commissioning a framework to provide DAH across healthcare organizations). Organizationally, institutions should adopt a wide approach to implementation of transition and young people's healthcare. A Transition Steering Committee—or similar set up, chaired by a Transition Coordinator, is one suggested means by which to facilitate this. Further, pediatric clinicians should plan Transition procedures jointly with the relevant named adult clinicians and general practitioners.

Prioritizing adolescent health training and incorporating it into all aspects of professional healthcare training is essential and long overdue. Good examples of training resources exist—(e.g., European training in effective adolescent care and health (EuTeach [42]) and E-learning for Health, adolescent health module)—but more needs to be done to ensure widespread access to training for healthcare professionals across child and adult services [14].

Current training in adolescent health and transition, in pediatrics and adult medicine, is still not fit for purpose in the UK and many other countries. For example, just under half of health professionals working in rheumatology clinics are unclear about transitional care issues, are ambivalent about their role and identify significant training needs [30, 43, 44]. Lack of training in adolescent development and health care has been reported as a major barrier to the implementation of transition [32]. Whilst specific health needs of adolescents have been clearly acknowledged and extensively documented [45–49] few pediatricians have received specific training in adolescent health.

Conclusion

Reid et al. have pointed out that the issues of transition are "discussed frequently … [but] studied rarely" [50].

Even though a number of chapters in this book attempt to do so, it is time that instead of trying to provide a good 'transition' we concentrate on ensuring that pediatricians and adult physicians improve their understanding of adolescent and young adult development and provide "good adolescent and young adult healthcare." There have been attempts to make this happen. The Children and Young People's Health Outcomes Forum is an independent group of experts from local government, the NHS and charities helping to develop a new strategy for improving care. In July 2012, they recommended four new indicators for inclusion within the NHS Outcomes Framework. Two of these are: (1) effective transition from children

Table 9.1 Basic principles of Adolescent Health and Medicine

Provide developmentally appropriate care
Enhance patient autonomy
Ensure collaboration between healthcare providers
Teach skills of negotiation
Gradation of responsibility to the adolescent
Provide community resources
Designated professional who takes responsibility for transition
Provide patient a portable summary of their healthcare needs
Have current transition plan documented

to adult services and; (2) age-appropriate services, with particular reference to teenagers.

More recently in 2014 the Care Quality Commission (CQC) published a report on transition with a key quote:

> … good transition arrangements may raise a provider's rating, and poor practice may reduce it. We may take action in cases where arrangements are so poor that they pose a risk to the quality of care experienced by people who use services [51].

Rather than continually reviewing transition we should encouraging young people to become "independent managers of their health care personal mastery!!" [52].

Numerous guidance documents contain suggestions for addressing the developmental needs of young people that have been overlooked by focusing on the organizational matters of transfer. We agree that all young people should know well in advance that the location of their care will change and preparation for this should happen. However, we propose that this should occur as a matter of course, embedded within a framework of quality adolescent and young adult healthcare. The way in which we do this is enshrined in the Society for Adolescent Health and Medicine [53] (Table 9.1).

What Needs to Be Done

Adolescent Healthcare Provision: Key Practice Points

- Professionals working with young people (aged 11–25) should seek additional training in adolescent health and development (e.g., http://www.e-lfh.org.uk/projects/adolescent-health/. and http://www.unil.ch/euteach)
- Making Healthcare Work for Young People: A Toolkit to support delivery of developmentally appropriate healthcare in the NHS (https://www.northumbria.nhs.uk/sites/default/files/nhs-making-healthcare-work-web.pdf)
- Young people will want to discuss their health condition in the context of their daily life

- Individual time within the consultation separate from parent(s)/carer(s) should be offered to young people, based on their readiness and preference.
- The parameters of confidentiality should be discussed with young people in the first consultation, with reminders at periodic points throughout adolescence.
- Parent(s)/carer(s) will continue to need to be involved to support the young person.
- Skills in facilitating this triad of communication (young person-parent(s)/carer(s)-professional) are required by health care professionals, in order to co-create the agenda of the consultation.
- Future research needs to capture the detail and complexity of interventions pertaining to the more nuanced, developmental aspects of young people's healthcare. There has been a call [54] for future research to be led by staff trained to work with young people and with a nuanced knowledge of the barriers that impact negatively on their care.

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