A multi-method review to identify components of practice which may promote continuity in the transition from child to adult care for young people with chronic illness or disability

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Executive Summary

Background

The number of young people with chronic diseases and disabilities entering adulthood in need of supportive care is increasing. There is evidence to suggest that services are failing to manage this transition effectively, with the result that the health and well-being of these young people is compromised and their potential unrealised. Efforts should be made to ensure that young people and their families are supported during the transition, building a firm foundation for their adult life. As a first step toward better transitional management a review of current practice was commissioned by the National Co-ordinating Centre for NHS Service Delivery and Organisation (NCCSDO). This report details the findings of that review.

Aims

The review aimed:

- firstly, to identify practices which address continuity during the transition from child to adult care

- secondly, to assess the merits of those practices, determining (evidence permitting) good practice.

The review also sought to identify any underlying mechanism or models which may be useful in developing continuity.

Method

A multi-method approach for the identification of practices promoting continuity was adopted, using multiple searches with distinct but complementary strategies. The following three search strategies were employed:

- a systematic review of effectiveness focusing on the identification of good practice models

- a systematic literature review focusing on five tracer conditions: diabetes mellitus, learning disability, cystic fibrosis, congenital heart disease and muscular dystrophy

- a review of established research and practice networks based on contacting key stakeholders and a survey of two large metropolitan areas.

The outputs from the searches comprised journal papers, written reports and survey data, and were termed 'items'. Each item was examined to identify what the practice or practices were within it. The methods used to support or promote the identified practice were also appraised. Once all the items had been examined and appraised, and the practices identified, a thematic analysis was undertaken to locate those practices under headings that captured the core elements of those practices.

Main outputs

A large range of different practices were identified by the review which were organised into three main domains reflecting the primary focus of the practice, comprising the service, the young person and the family. The practice components identified in the service domain were sub-categorised into structures, processes and outcomes. The main outputs from this part of the review were as follows.

- Structural components included: transitional workers; transitional teams; professional continuing education; information for professionals; use of existing continuous services; inter- and intra-organisation liaison and agreements; organisational planning; frameworks; and fostering equity and accessibility.

- Process components included: preparation for transition; active management of transition; case management; accountability for the process; strong therapeutic relationships; advocacy; joint management of care; flexibility regarding point of transfer; specific communication systems; and regular audit of service provision.

- Outcome components were either disorder-specific or generic such as user satisfaction. Outcome components provide benchmarks against which service quality may be measured.

- Components of practice regarding young people include: specific service provision; development of skills of self-management and self-determination; support for psychosocial development, involvement of young people; peer involvement; support for changed relationships with parents/carers; provision of choice; provision of information; and focus upon the young person's strengths for future development.

- Components of practice regarding parents and carers include: support for adjustment to changed relationships with young people; parental involvement in service planning; family-centred approach; and provision of information.

In addition to these components of practice a service development framework based on a seven-stage process for addressing continuity has been constructed.

Components of practice in the transition from child to adult care

1   Identifying the care group or user population.

2   Identifying the key dimensions of the transition.

3   Involving stakeholders.

4   Identifying transitional needs for each dimension of the transition.

5   Transitional planning at the individual, organisational and inter-organisational levels.

6   The provision of the appropriate resources to support the transitional plans.

7   The evaluation of the transition at each proposed level.

Four models of continuity promotion were also identified during the analysis.

1   Direct transition – focusing on good and communication and inter-agency collaboration.

2   Sequential transition – developing special services for young people to help them adjust to adult care.

3   Developmental transition – providing specific support to help young people develop physically, psychologically and socially in adapting to their new care role and in maximising their potential.

4   Professional transition – flexibility in moving expertise between child and adult services.

Limitations of the review

- A paucity of high-quality primary research.
- A focus on explicit rather than implicit practices.
- The assignation of strength of evidence was at the methodological level.
- No external validation of the coding schedule developed as part of the thematic analysis.

Recommendations

- Continuity in the care transition must be examined in parallel with the young person's physical, social and psychological growth and development.
- Continuity at transition is multidimensional and researchers and practitioners should try to account for all these dimensions even when focusing on only one or two.
- Practitioners and researchers need to be specific about the dimensions of continuity which they aim to address.

Components of practice in the transition from child to adult care

- The components for practice, framework and models of continuity promotion developed through this review need to be further refined and explored through primary research in practice settings.

- Continuity at transition needs to consider the perspectives of the services, the young person and the family.

- In reporting or evaluating an intervention or practice aimed at addressing continuity through the transition, the following factors should be considered and addressed in the report:
  – the nature of the user population
  – the dimensions of continuity being addressed
  – a careful description of the structure and process of the intervention
  – for multiple interventions or whole programmes, examination of both the individual and aggregate impact of the elements within the programme
  – outcome measures which are appropriate to the dimensions of continuity being examined
  – following the young person through the transition and, where feasible, long-term follow-up.

The Report

1 Introduction

The journey into adult life is a time of profound psychological and social change which is a very challenging time for young people and their families. For young people with disabilities or chronic diseases the transition is made more difficult because it is often accompanied by significant changes in their care needs and provision. The young person's role in the management of their disease or disability is also likely to change because they will often both desire and have to take a more active role independent from their parents.

Despite the importance of this transition, many young people and their families experience difficulty in gaining the health and social support which they require. A breakdown in continuity at this point can impact negatively on clinical outcomes, sometimes putting the person at risk, and may have repercussions on long-term health and social well-being. Thus, developing continuity through this transitional period is an important objective, both to enhance the effectiveness of the health and social care provided and to minimise any uncertainty or distress for young people and their families.

This report identifies key components of practice in relation to the continuity of care for young people with disabilities or chronic diseases during the transition from child to adult provision. The components identified are based on an extensive review of current research and practice. The report primarily addresses health and social care provision although educational provision was also found to be important. The report describes the process through which the components of practice were identified, discusses their implications and makes recommendations for their future development and evaluation. Limitations of the review are also acknowledged.

1.1 Young people in transition

Allied to improvements in health care, an increasing number of children with conditions previously associated with poor life expectancy are surviving into adulthood (While *et al.*, 1996). Chronic diseases which develop in childhood and need lifelong management are also increasing (British Paediatric Association (BPA), 1990; Betts *et al.*, 1996). In addition, there are a number of different groups of children with other disabilities which require lifelong care (Metcalfe and Baum, 1991; Gardner *et al.*, 1997). This means that there is a significant population of young

people with a wide range of different needs requiring the support of services to achieve their physical, social and psychological potential.

In considering the needs of young people during the transition it is important to view those needs within the context of their social development (James and Prout, 1990). Relations with family members and peers are likely to have an important influence on young people and their experience of continuity during this period of transition. Indeed, the provision of informal care, through parents or guardians, may be the only level of care provision at which any degree of continuity is established. It is also important, however, to appreciate that the transition is about the need for the young person to establish themselves as an autonomous being, independent from family interests and control.

1.2 Issues for transitional care provision

Significant improvements in the care and support offered to children and their families have been achieved in recent years. However, there is evidence to suggest that such improvements are not being sustained during the difficult transitional period from child to adult provision (Morris, 1999; Noyes, 1999; British Paediatric Association (BPA), 1990; (Association of Children with Life-Threatening or Terminal Conditions (ACT) and the Royal College of Paediatrics and Child Health (RCP & CH), 1997; House of Commons (HOC), 1997a; HOC, 1997b; Goodinge, 1998; Fruin, 1998). While this may in part be attributable to the general paucity of adult services in many fields, it also reflects a failure to manage and integrate care effectively during the transition. Furthermore, there is concern that a significant proportion of young people with ongoing needs become dislocated from the care system during this period.

Service configurations are sometimes unhelpful to the achievement of continuity of care between child and adult services because they frequently involve different care plans, care teams and funding arrangements. Further, an arbitrary age point assumes that chronological age alone indicates a readiness for transfer, which may disregard the complexity of adolescent development.

Transition may be further complicated by the disorder trajectory. For example, young people with congenital heart disease may have advanced heart failure for which a transplant or other major surgical intervention presents the only opportunity for survival. In the case of other disorders where there are often many different agencies involved, communication and management can become even more complex. Someone with a learning disability may require the support of a multi-agency package of care, with each participating organisation often having different rules and practices regarding the transition. The transition may also have financial implications, impacting on welfare benefits and care funding arrangements. In disorders requiring intensive therapy or access to equipment – such as cystic fibrosis or muscular dystrophy – continuity may create uncertainty about who has the responsibility for providing such resources. In all of these cases the transition is a time of great

stress because many of the systems upon which these young people have grown to depend are to be withdrawn.

This stress may be compounded by the inherent difficulties of the adolescent phase. Clearly a core element of transitional care must be the provision of services which reflect the changing status and outlook of the young person. This needs to include a consideration for the parent or guardian of the young person because they must also adjust to a new role.

The breakdown of care between child and adulthood is, therefore, a multi-faceted and multilevel problem. Fault lines can be seen at a number of levels, between:

- child and adult services (both social and health)

- primary and secondary/tertiary care

- the local authority, health services and the private and voluntary sectors

- service users and service providers

- young people and parents.

A failure to address these fault lines may mean that any gains made by children's services are undermined or lost and, more importantly, that young people and parents experience unnecessary distress. Figure 1.1 further illustrates factors which are influential in the transition from child to adult care.

Figure 1.1 Factors affecting the quality of transition

Organisation of transferring

Relationship to care services

Current service organisation

Psychological factors

and experience of it

Stability of condition

Care

Experience of the transition from childhood to adulthood

Duration of disability or ill health

Quality of transition

Disability or ill health experience

Demographics

Paediatrics – Adult services

Disorder treatment, adherence and experience

Relationship to parents/partner

Complications

Peer group

Support sources/access

1.3 Policy

The review was conducted during a period of major policy development in health, social services and education. Many of these policies will impact either directly or indirectly on continuity in transition from child to adult care. The National Service Frameworks (NSFs) and the development of combined health and social care organisations in the form of social care trusts (SCTs) may have a particularly important impact. For example, Standard 6 in the NSF for diabetes states that:

> *All young people with diabetes will experience a smooth transition of care from paediatric diabetes services to adult services.*

> (DoH, 2002:5)

The government has set up a number of groups to help steer these developments, primarily through the Children and Young People's Unit (Children and Young People's Unit, 2001) which is attempting to develop 'joined-up' policy making and service delivery, so overcoming some of the current barriers to effective working. The Children and Young People's Unit also has a role in engaging users and the voluntary sector in development and delivery of services so that practices reflect the needs and priorities of young people themselves. Concurrently a Children's Taskforce is charged with examining how the NHS Plan (Department of Health (DoH), 2000) relates to children and their families and how health and social care services may deliver effective high-quality services. Additionally, a Children's National Service Framework is currently being developed which will set out benchmarks for service delivery, including transitional arrangements.

In the area of disabilities a number of particular policy initiatives may make an important contribution to the development of continuity. Some guidance regarding transition arrangements is available within *Valuing People: a New Strategy for Learning Disability for the 21st Century* (DoH, 2001) and the *Special Educational Needs (SEN) Code of Practice* (Department of Education and Skills (DES), 2001), both of which acknowledge the importance of continuity of support and equality of opportunity. To this end the Connexions Personal Advisors scheme is being established, which will work with young people with statements of SEN in drawing up transition plans which will form a key focus of the annual review meeting in 'year 9' (school year). Both sets of guidance emphasise the involvement of young people and their families in the transition process, in addition to other key support services including health and social services where appropriate. Increased levels of disability may require more support which may be assessed under Sections 5 and 6 of the Disabled Persons (Services Consultation and Representation) Act 1986 for the young person or Section 4 of the Carers and Disabled Children's Act 2000 for the family. Consistently, Social Services Inspectorate (SSI) reports have highlighted the need to tackle barriers impeding effective working between health, social services and education if services for children and young people with disabilities and their families are to benefit from co-ordinated packages of support. The review was undertaken against this policy background.

1.4 Continuity

Continuity is a difficult concept to define and has different emphases within different care settings. Continuity is regarded within this review as managing the complex dynamics at work during the period of transition from child to adult care. These dynamics are expressed in the relationships between services and in the different views of the professionals, young people and families involved.

The six dimensions of continuity identified by NCCSDO's scoping exercises provided a conceptual framework for the organisation of the review and in the analysis of the identified materials (Freeman *et al.*, 2000).

- *Experienced continuity* – the experience of a co-ordinated and smooth progression of care from the service user's point of view.

- *Continuity of information* – excellent information transfer following the service user.

- *Cross-boundary and team continuity* – effective communication between professionals and services and with service users.

- *Flexible continuity* – flexibility and adjustment to the needs of the individual over time.

- *Longitudinal continuity* – care from as few professionals as possible, consistent with other needs.

- *Relational or personal continuity* – one or more named individual professionals with whom the service user can establish and maintain a therapeutic relationship.

These dimensions have been particularly useful in determining the range of practices examined by the review.

However, in undertaking the review it became apparent that these dimensions alone were not able to represent fully the dynamic relationships identified as core to the experience of continuity in the transition from child to adult care. It was also felt that these dimensions were not useful in organising the key components identified and reflecting the multifaceted nature of many of the interventions identified. Therefore, a simpler framework which accounted for the dynamic relationships in the transition was adopted. This framework is based upon three overlapping domains into which practices aimed at enhancing continuity can be located. The three domains are:

1   *the service* – practices relating to the structure and process of care delivery, including the relationships between different services, agencies and professionals

2   *the young person* – practices aimed at the development of the young person

3   *the family* – practices aimed at supporting families in adjusting to new roles and care arrangements.

1.5 Scope of the review

The scope of the review was wide ranging, examining practices which aim to promote continuity for a number of different care groups in both health and social care settings. A number of specific 'tracer conditions' in which continuity of care is a particular issue were included to allow for a more in-depth exploration of continuity in those areas. These conditions were:

- diabetes mellitus

- learning disability

- cystic fibrosis

- congenital heart disease

- muscular dystrophy.

The emphasis of the review is on the identification of elements of practice. While there is a body of literature relating theoretical models for continuity and views of what continuity entails, unless those models or views identified specific practices they fell outside the scope of this review. For example, an author may suggest that empowering the young person is important; however, the concept of empowerment alone does not translate into good practice unless some indication is given as to how this should be achieved. The rationale for this distinction is not to negate the importance of such theory but to maintain a clear focus on 'good

practice' rather than 'good theory'. However, in the best examples, the two often coexist.

It is important to recognise that accounting for every element which may contribute to good practice in managing the transition from child to adult care is unrealistic. This review was restricted to reporting explicit practices which were argued to have a positive effect on improving continuity in that transition. The review was further confiined to those practices reported in the literature or those identified from the limited survey conducted as part of the review.

Thus, certain elements of care may not have been identified by the review because many key practices may be so habituated as to be obscured. For example, the impact and enthusiasm of one dedicated practitioner is rarely reported, even when such a person can have a profound effect on improving continuity. Another example might be the correspondence between the hospital specialist and the general practitioner, something which is important to continuity but so common that it may be overlooked. Such elements are often implicit to care, so that it is difficult to account for them. These practices were unfortunately beyond the scope of this review unless they were identified in the literature and as a result there is probably a bias toward reporting what is explicit, novel and innovative.

1.6 Aim and objectives of the review

The aim of the review was twofold: firstly, to identify practices which address continuity during the transition from child to adult care; and secondly, to assess the merits of those practices determining good practice. Good practice was to be determined at two levels.

- The first level relates to the specific practices identified, many of which were linked to particular populations and practice contexts.
- The second level relates to the need to identify overarching themes expressing the common components of good practice in promoting continuity in general terms.

In this report the emphasis is on the second level, since it is here that the more transferable elements of practice are related, although specific practices will be used as examples.

It is acknowledged that identifying what constitutes good practice is contentious, something which is particularly true when examining the diverse range of practices which may or may not promote continuity in the transition from child to adult care. This task is made more difficult by the divergent philosophical and methodological approaches utilised in the description and evaluation of continuity practices. There are particular differences between health and social care evaluations, with health services research tending to be biased toward bio-physiological outcomes and social services research tending to focus upon process variables. Thus, the assessment of what constitutes good practice has been one of

the most challenging aspects of the review. The review's objectives were to:

- identify literature, research and practice relevant to the scope of the review, following an explicit search strategy

- critically appraise the items identified in the search

- identify the key components of good practice for promoting continuity (reflecting the definition of continuity detailed in Section 1.3.)

1.7 Summary

The number of young people with chronic diseases and disabilities entering adulthood in need of supportive care is growing. There is evidence to suggest that services are failing to manage this transition effectively. As a result of this failure, the health and well-being of these young people are compromised and their potential is going unrealised. Efforts should be made to ensure that young people and their families are supported during the transition, building a firm foundation for adult care provision.

It is intended that this report will be a useful guide for those involved in planning and delivering services during the transitional period, offering a range of potential strategies which may help promote a greater degree of continuity.

2 Method

Reflecting the broad scope of the review, a multi-method approach for the identification of practices which may promote continuity was adopted. Given the diffuse nature of the field of inquiry it was felt that multiple searches with distinct but complementary strategies would yield more useful data than traditional secondary analysis approaches pursued in isolation, such as systematic review. However, many of the key principles of systematic review were utilised in constructing the search strategies and in appraising items (Chalmers and Altman, 1995). Three search strategies were employed:

1   a systematic review of effectiveness, focusing on the identification of good practice models

2   a systematic literature review, focusing on five tracer conditions: diabetes mellitus, learning disability, cystic fibrosis, congenital heart disease and muscular dystrophy

3   a review of established research and practice networks, based on contacting key stakeholders and a survey of two large metropolitan areas.

It was envisaged that while each of these searches would generate interesting findings, their collective output should ensure a more comprehensive, detailed and valid account of practices than would any one single approach. The outputs from the searches comprised journal papers, written reports and survey data and were termed 'items'. Each item was examined to identify what the practice or practices were within it. The methods used to support or promote the identified practice were also appraised. Once all the items had been examined and appraised, and the practices identified, a thematic analysis was undertaken to locate those practices under headings which captured the core elements of those practices. An overview of the design is presented schematically in Figure 2.1.

Figure 2.1 Overview of research design
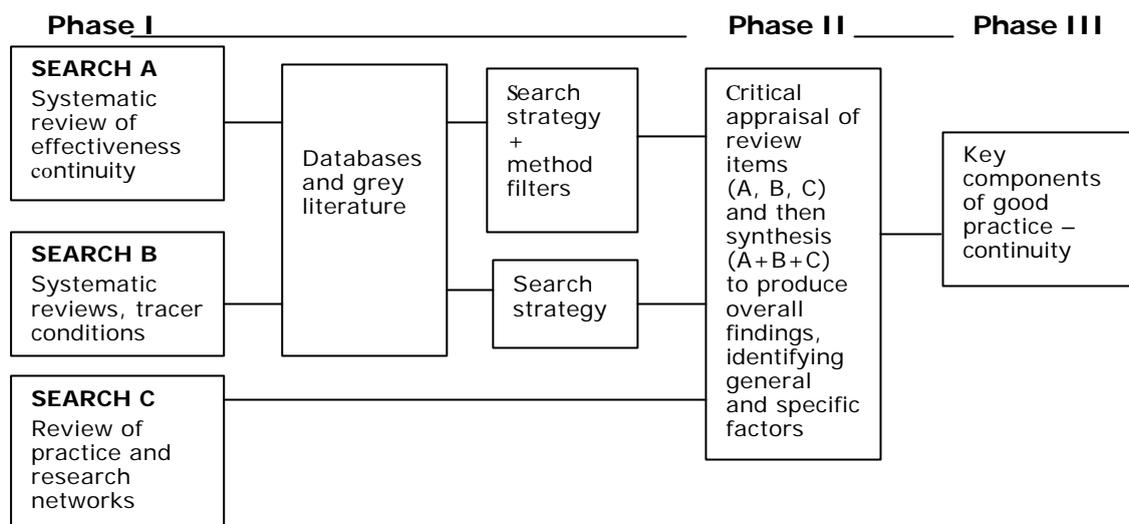
These methods were executed in three phases following the review's objectives:

Phase I Identifying practices

Phase II Critically appraising practices

Phase III   Identifying the key components of good practice.

2.1 Phase I: Identifying practices

The method and execution of each search is described below:

Search A: A systematic review of effectiveness to identify practices which promote continuity

The search aimed to identify any practices relating to continuity or the management of the transition which had been subjected to some form of evaluation or assessment. The emphasis on evaluation reflected the need to report or make some judgement on what is good practice. Evaluation is clearly one way in which such an assessment can be undertaken. In this search no restrictions were placed on the field of the young person's health or social care examined, although items generated were restricted to evaluative studies. The search followed an explicit schedule based on key search terms. These terms were divided into the target population and the key facet, continuity, with a list of synonyms being generated for each (Appendix 1 details all the search terms employed in the review). These included both free text and indexed terms, all of which were combined to form a connected search command chain. The search terms were agreed by the project team. Terms were not externally validated, although the project team had extensive expertise in the field of study. A methodological filter was used (the EPOC filter, see Appendix

2) to ensure that only items relating some level of evaluation were included.

Each strand of the search (the target population, the key facet and the methodological filter) was then combined using the appropriate Boolean operators. A broad range of electronic databases relevant to both health and social care were searched, including specialist databases (see Appendix 1 for full details). The searches were conducted by two librarians and two researchers.

The preliminary list of items identified by the search were then filtered down to a list of papers for retrieval. This involved two researchers examining the titles and abstracts of papers, identifying those which either did not deal directly with continuity or management of the transition or did not describe specific practices. Inter-rater reliability was assessed on a sample of abstracts (n = 118) and calculated to be 0.81.

Each retrieved item was coded, described and then logged onto a computer reference manager. Secondary references were pursued, although owing to time constraints this was not consistent or systematic enough to ensure completeness. While the search was limited to English-language papers published within the past 20 years, a number of mainly European papers which seemed particularly promising were translated.

Search B: A systematic literature review focusing on five tracer conditions

While Search A aimed to identify practices based on evidence, this search sought to identify a broader range of practices linked to contrasting disorders in which continuity of care is particularly important. Five tracer conditions were used to guide the search: diabetes mellitus, learning disability, cystic fibrosis, muscular dystrophy and congenital heart disease. These disorders were identified not only because of their prevalence in childhood, but also because they transcend the spectrum of health service provision covering health promotion, screening, acute care and long-term management. In addition, it was hoped that these disorders would highlight the different interface factors which may be specific to primary and secondary health care settings. These disorders also fulfilled a number of other criteria which make them useful as tracer conditions, in that: they are easy to define; they are amenable to improvement; there are criteria for distinguishing between high- and low-quality care; and non-medical factors can be identified (Kessner and Kalk, 1973). Thus, these disorders should have been helpful in distinguishing good practice. The search followed the same process as described for Search A without the methodological filter to ensure a wider range of literature was included and with the addition of SIGLE (grey literature) to the core list of databases. The search terms used for the tracer conditions are also detailed in Appendix 1.

Search C: A review of established research and practice networks

This search aimed to identify practices which were not revealed in the literature, recognising that many examples of practice may be unpublished. There were two main elements to this search: firstly, contact with key informants or stakeholders; and secondly, a survey of services involved in the commissioning, management or provision of care for young people in the Greater London and Manchester areas.

Key informants and stakeholders were contacted directly by telephone and asked whether they knew of any practices, documents or reports focusing on continuity in the transition of care. If written materials were identified, they were forwarded for inclusion in the review. Some informants suggested secondary contacts who were also pursued. (A full list of the organisations contacted is detailed in Appendix 3.)

A survey questionnaire was developed to identify current practices in relation to the transition (Appendix 4). The questionnaire comprised a number of predetermined categories based on known practices together with open-response items to permit the identification of any other practices. The questionnaire used the tracer conditions to help focus responses. If specific practice initiatives were identified, respondents were asked to return any documents describing those practices and their evaluation with the questionnaire. The questionnaire was reviewed by the project team and piloted in four areas before being administered to the whole sample.

The questionnaire was mailed to named health, social services or education staff working with children and young people with chronic illnesses and/or disabilities across the two geographical areas (n = 244). (A list of all the services included in the survey is contained in Appendix 5.) The questionnaires were mailed with a covering letter and an information sheet. Non-responders were contacted by telephone after three weeks and repeat questionnaires were mailed as requested.

2.2 Phase II: Critically appraising practices

Items identified by the searches which could be retrieved either directly or through the university library, specialist libraries (e.g. National Children's Bureau) and the British Library were then critically appraised. The critical appraisal aimed, first, to identify the practice or practices being described and, second, to examine the quality of the evidence used to support those practices. To facilitate this appraisal a number of assessment schedules were developed (Appendix 6). These schedules also helped standardise the process as three researchers appraised papers independently. Again, inter-rater reliability in the use of these schedules was assessed on a small sample of items (n = 3) and each of the reviewers independently located the papers within the same categories.

All items where appraised using the 'item assessment schedule' (Appendix 6.i) which retrieved the main components of the item. This schedule was used to classify the item into one of four categories denoting the manner in which the practice was presented and supported. The categories were:

1   *Description* – an item describing practices

2   *Evaluation* – an evaluation of practices

3   *Survey/Interview* – a survey or interview with service users from which practices were suggested

4   *Review* – an item reviewing previous literature (theory and practices) suggesting specific practices.

The item assessment schedule was also used to identify the key elements of practice contained within the item, including:

- the target population (care group and age range)

- a general description of the practice, together with any sub-components

- where the practice was located

- structure, process and outcome variables

- economic data

- the role and involvement of users.

If an explicit methodology was used to guide the evaluation, survey/interview or review, this was assessed to determine the strength of the evidence generated. Three further schedules were used for this assessment depending on the type of research: quantitative (Appendix 6.ii), qualitative (Appendix 6.iii) and review (Appendix 6.iv). The scoring systems within these schedules indicated the method as either 'weak', 'moderate' or 'strong'. It was envisaged that this grading, together with overall outcome of the practice (i.e. the degree of improvement observed), would be an important element in identifying the degree to which a practice was of value.

The content for these assessment schedules was derived from established appraisal guidelines. These guidelines where edited so that they could be used with the wide variety of source materials identified by the searches. It is acknowledged that in so doing some of the detailed focus of the original schedules may have been lost. Nevertheless, the core elements were retained and the schedules had greater utility with a broader range of items. The scoring system is based on a simple Likert scale and relied upon the assessor to attribute value. This naturally introduced an element of subjectivity, although the high inter-rater reliability suggested a good degree of constancy. However, dichotomous variables (i.e. yes and no) may have been more precise. The scoring system was not externally validated and there are internal inconsistencies with the schedules, because the weighting is the same for all the items despite the fact some are obviously more crucial than others. It would have been advantageous to have compared the

schedules with the original from which they were derived, using papers of externally established levels of quality, to improve their validity and reliability.

2.3 Phase III: Identifying the key components of good practice

Prior to this phase of the analysis the data were a disparate collection of practices, as detailed on the item assessment schedules. In this phase each of the practices identified on those schedules was described and coded. In many cases item schedules generated more than one practice code, since the interventions related were often multifaceted in nature. This generated an ongoing bank of codes linked to specific types of practices. The coding exercise was completed when all the practices had been accounted for.

Following this, a thematic analysis of the allocated types of practices was undertaken. The key question applied in this analysis was: 'what are the key features of the practice in relation to continuity?' In applying this question it was possible to group practices under thematic headings which related their core aspects and suggested the active mechanisms involved in addressing continuity.

Once the thematic headings were identified, it also became clear that there were relationships between these headings which allowed for further levels of organisation. For example, it was during this phase of the analysis that the three domains of continuity became apparent – namely, services, young people and families. A number of other groupings were identified within these domains, which have been used to help organise the findings of the review.

The coding and analysis schedule enabled a link between the identified themes and source items to be maintained. Thus, it is possible to report the number items, the weight of evidence, the key findings and the main care groups alongside each theme or component of practice. It is also possible to illustrate each of these themes with specific practice examples. The description, coding and thematic analysis were undertaken by two researchers who scrutinised each other's coding practices and collaboratively developed the thematic headings (or components of practice). The output from this process is reported in Section 3.4.

3 Findings

The review's findings are presented in four sections.

3.1 identifies the output from searchers A, B and C, detailing the number of items identified, retrieved and analysed.

3.2 provides a brief overview of the retrieved literature categorising the types of materials used in the review.

3.3 reports the findings from the survey undertaken as part of Search C.

3.4 outlines the main findings of the review following the thematic headings which articulate the key components of practice identified in supporting the transition from child to adult care.

3.1 Search results

A large number of items were identified, mainly in the form of literature from professional journals. However, Search C also generated a small number of reports describing initiatives which addressed the transition. The number of items identified are detailed in Table 3.1. The table illustrates the filtration process described in Section 2, delineating: the numbers of items identified by the search; those actually retrieved and critically appraised; and those which contributed to the thematic analysis (i.e. those which related an aspect of 'good' transitional practice).

Table 3.1 Search results

Search	Number of items identified	Number of items appraised	Number of items contributing 'good practice'
A	4,076	172	61
B	1,202	170	39
C	41	26	26
Total	**5,319**	**368**	**126**

The main reasons why papers were not selected for critical appraisal or were rejected following the critical appraisal were that they either did not describe practice or they did not address transitional care. However, some of the drop in item numbers between identification and appraisal is accounted for by duplicates which could not be easily adjusted for, because different search engines were used on some of the databases; a small number of papers also proved difficult to retrieve within the time frame. It is estimated that this contributes less than 10% of the change observed. Appendix 7 provides a more detailed breakdown of item sources.

3.2 Overview of items

As described in Section 2.2, the retrieved items (papers and reports) were organised into four main categories: descriptions, evaluations, user accounts and reviews. The proportion of papers accounted for by these categories is illustrated in Figure 3.1.

Figure 3.1 Types of papers/reports
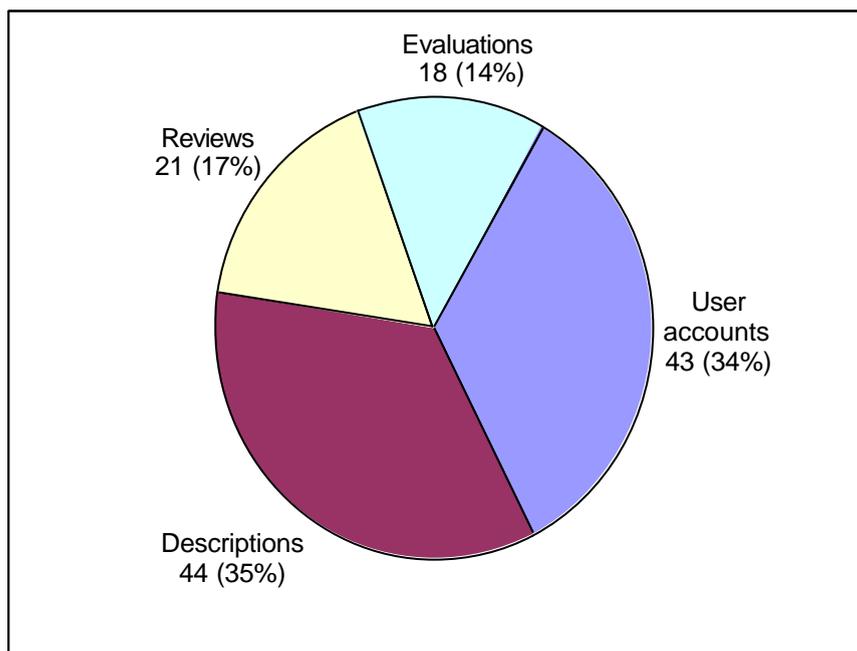
Those items falling into the descriptive category described an intervention or group of interventions which addressed the transition but did not report any data on the impact of the intervention.

Evaluation items were those in which some attempt had been made to assess either the process or the outcome of the intervention. Following an assessment of the methods employed, the evaluative items were sub-categorised as being either weak, moderate or strong, indicating the strength of evidence supporting the intervention (using the schedules described in Section 2). The numbers of items which fall into these sub-categories are set out in Figure 3.2.

Figure 3.2 Evaluation items (strength of evidence)
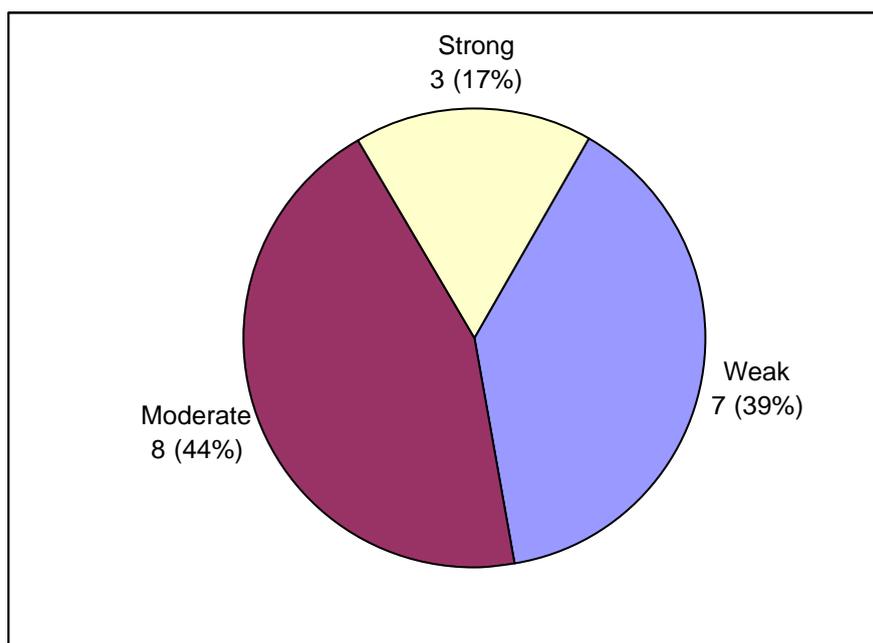
The majority of studies identified in the evaluation category were classified as either weak or moderate, reflecting the low number of externally based, well-designed experimental studies with comparison (control) groups or qualitative studies. Most of the reports detail internally based evaluations of process or before-and-after studies assessing only a limited range of outcomes. None of the evaluative studies provided detailed economic data or analysis.

User accounts were derived from either questionnaire or interview surveys and were of variable but generally limited rigour. These items often attempted to infer how practice could be improved to provide greater support through the transition.

The review items were generally theoretical discussions, with some making reference to evaluative studies to support their theoretical arguments, but no systematic reviews were identified. While purely theoretical reviews were outside of the scope of this review, they were included if they identified specific practice recommendations.

3.3 Survey findings

The overall response rate was 50% (n = 111) with the highest response rate coming from health services (Table 3.2).

Table 3.2 Response rate by service group

Services contacted	Number of responses from each group	Contribution to overall response rate
Health services	68	61%
Social services	29	26%
Education services	14	13%

The majority of respondents were involved in service delivery, although the poor response rate from commissioning services may reflect the major re-organisation which was taking place during the survey period, i.e. the shift from health authorities to primary care trusts (PCTs) (Table 3.3).

Table 3.3 Response rate by service type

	Commissioning n (%)	Planning n (%)	Managing n (%)	Providing n (%)
Yes	28 (25)	59 (53)	73 (66)	73 (66)
No	80 (72)	49 (44)	35 (31)	35 (31)
Unknown	3 (3)	3 (3)	3 (3)	3 (3)

The responding services were responsible for providing care to a wide range of young people with different conditions (Table 3.4). The tracer conditions identified for the review were given as pre-set categories, although respondents were asked to detail any other groups of users to whom they provided care. The 'other' category comprised: acquired heart problems, spina bifida, asthma, eczema, epilepsy, oncology, autism, attention deficit disorder, challenging behaviour, sensory impairment, blood disorders, mental health problems, disaffected young people and those with child protection needs. The high proportion of respondents working with learning disability clients reflects the strong focus on transition in this field.

Table 3.4 Response rate by condition (%)

	Congenital heart disease	Cystic fibrosis	Diabetes mellitus	Learning disability	Muscular dystrophy	Physical disability	Complex problems	Other
Yes	54(48)	45(40)	39(35)	88(79)	64(58)	81(73)	82(74)	50(45)
No	54(48)	63(57)	69(62)	20(18)	44(39)	28(25)	26(23)	58(52)
Unknown	3 (4)	3 (3)	3 (3)	3 (3)	3 (3)	2 (2)	3 (3)	3 (3)

As part of the survey, respondents were asked to detail what happened to service users at the point of transition. The majority of services either handed patients over to adult providers or provided transitional care, although between 10% and 20% of services simply discharged clients or provided no handover (Table 3.5).

Table 3.5 Current transitional care (%)

	Client discharged	No handover	Handover	Transitional care arrangements	Not applicable	No response
Congenital heart disease	5 (9)	8 (15)	17 (31)	14 (26)	3 (6)	7 (13)
Cystic fibrosis	2 (4)	1 (2)	20 (44)	16 (36)	2 (4)	4 (9)
Diabetes mellitus	2 (5)	2 (5)	14 (36)	15 (38)	3 (8)	3 (8)
Learning disability	3 (3)	9 (10)	33 (38)	38 (43)	1 (1)	4 (5)
Muscular dystrophy	3 (5)	6 (9)	28 (44)	16 (25)	3 (5)	7 (11)
Physical disability	2 (3)	9 (11)	37 (45)	26 (32)	2 (3)	5 (6)
Complex problems	1 (1)	8 (10)	31 (38)	39 (48)	0	3 (4)

Respondents were using a range of different approaches to manage the transition. The most common approach involved joint working between child and adult services although, since that category was not defined, the extent or form of this joint working was unclear (Table 3.6). However, in the 'Other' category some more innovative approaches were identified and comprised:

• a parent advisor (n = 1)

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- transitional workers (n = 10)
- transitional protocols (n = 2)
- multi-agency transitional planning and review group (n = 1)
- transitional assessments, reviews and panels (n = 6)
- summary reports (n = 1)
- educational sessions and workshops for young people (n = 2)
- young adult clinic (n = 1)
- liaison with primary health care teams (n = 1)
- supported social programmes such as work placements (n = 2)
- a professional forum to discuss transitional issues and cases (n = 1).

Table 3.6 Approaches to the transition

	Health services	Social services	Education services	Total
Transition team	13	11	1	25
Joint working adult and children's services	39	24	5	68
Partnership approaches with young person	18	15	6	39
Shared documentation/ record keeping	9	9	1	19
Out of clinic support groups	6	5	1	12
Other	12	10	6	28

Less than one-quarter of respondents (n = 24, 22%) had evaluated their transitional care provision and only 17 (15%) had produced a written report of their evaluation, 14 of these reports were forwarded and included in the review (Table 3.7).

Table 3.7 Descriptions or evaluations of transitional approaches

	Evaluations conducted	Reports written
Health services	12	9
Social services	12	8
Education services	0	0

3.4 Key components of practice

The results of the thematic analysis are presented as a series of headings denoting the 'key components of practice'. As suggested in Section 2, these headings have been further organised into three domains relating to the service, the young person and the family. Within these domains further subdivisions have been identified to help structure the material. Table 3.8 summarises the findings using that structure.

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Table 3.8 Key components of practice (thematic headings)

3.4.1 Services

3.4.1.1 Structure

    3.4.1.1.i Transitional workers

    3.4.1.1.ii Transitional teams

    3.4.1.1.iii Transitional services

    3.4.1.1.iv Developing professional awareness, knowledge and skills

    3.4.1.1.v Provision of information for professionals

    3.4.1.1.vi Using continuous services to provide bridge (e.g. primary care)

    3.4.1.1.vii Intra- and inter-organisational (agency) liaison and agreements

    3.4.1.1.viii Organisational planning

    3.4.1.1.ix Organisational frameworks

    3.4.1.1.x Accessibility and equity

3.4.1.2 Process

    3.4.1.2.i Preparation for the transition

    3.4.1.2.ii Managing the transitional process

–   Assessment (identifying needs other than clinical)

–   Planning and goal setting

–   Review short and long term

    3.4.1.2.iii Case management

    3.4.1.2.iv Accountability for process

    3.4.1.2.v A strong therapeutic relationship

    3.4.1.2.vi The need for advocacy

    3.4.1.2.vii Joint care management

    3.4.1.2.viii Flexibility in point of transfer

    3.4.1.2.ix Specific communication systems and documentation

    3.4.1.2.x Regular review/audit of service in relation to transition

3.4.1.3 Outcomes

–   Clinical outcomes improved or maintained

–   Young person/family satisfaction (expectations are met)

–   Young person/family knowledge

–   Young person is able to adopt adult roles

–   Young person becomes self-determining in the management of their condition

–   Examining outcomes in the long term

Table 3.8 Key components of practice *(continued)*

3.4.2 Young people

3.4.2.1 Specific services which reflect the lives and needs of young people

3.4.2.2 Development of skills for independence in life and in managing their condition

3.4.2.3 Development of self-determination and autonomy

3.4.2.4 Supported psychosocial development in the transition

3.4.2.5 Involvement of young people in organising services

3.4.2.6. Peer involvement

3.4.2.7 Support of young people to develop a new relationship with their parents/carers

3.4.2.8 Provision of choices

3.4.2.9 Provision of information

3.4.2.10 Focus on strengths

3.4.3 Families

3.4.3.1 Support for parents and carers in adjusting to change

3.4.3.2 Parental involvement in service planning

3.4.3.3 Family-centred approach

3.4.3.4 Information for families

Each key component is illustrated with some of the practices from which it has been derived, together with its frequency, care group base and the strength of evidence supporting it. A table containing the details of all the items used within the analysis is provided in Appendix 8. This table gives a brief description of each item and its contribution. Each item is numbered and used to identify the source items within each component, which enables the reader to link the key components to the specific practices from which they were derived. In presenting these data it is possible to determine those components of practice which are more common and those supported by stronger evidence. In some cases the amount of evidence supporting a given component is limited to only one or two items. These components were included because they presented a unique feature of practice in relation to continuity through the transition, although it is acknowledged that they are more tentative than more commonly identified components. However, given that some components of practice are more established and are based on or have been assessed by more rigorous methods, the potential benefits, limitations and application for each component is included in the commentary, although ultimately the utility of these components is dependent on needs and circumstance of the population of young people and the practice area. In addition, seven case studies were also identified; these studies were selected because they present interesting examples of different practice components as they are used in practice.

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3.4.1 Services

The service domain is the largest and most complex of the three. The practice components that comprise the service domain can be placed in one of three sub-categories: 'structure', 'process' and 'outcome'.

3.4.1.1 Structural components

Structural components of practice are those which create the opportunities for continuity, such as: the provision of the necessary physical and human resources; the development of agreements and contracts between and within agencies; the organisation and provision of services; and channels of communication.

3.4.1.1.i Transitional workers

Type and volume of items supporting component (theme)

Type of item	Description	Evaluation			Survey/ interviews			Reviews			Total
Strength		S	M	W	S	M	W	S	M	W	
No. of items	9	0	1	3	1	0	4	0	1	2	21
Item codes (referenced in Appendix 8)	14, 17, 18, 23, 24, 32, 34, 36,42, 46, 48, 61, 65, 75, 85, 88, 105, 112, 118, 119, 124										
Care Groups	Diabetes mellitus, learning difficulty, homeless/street youth, HIV and AIDS, spina bifida, visual impairment, general disability and chronic illness, behavioural disorders, sickle cell anaemia, chronic renal disease										

Key: S= Strong, M= Moderate, W= Weak – indicating strength of evidence.

Transitional workers come in many guises with a number of different roles depending on the context in which the post has evolved. Transitional workers can be found in education, social and health care settings. In health care-based services the person most frequently linked with this role is a specialist nurse. However, despite this heterogeneity there are a number of unifying characteristics associated with these posts and their impact on continuity. 'Planning' transitional care is central to all of these posts, making the connection between child and adult provision, a role which is seen as particularly important where complex needs are involved. 'Co-ordination' is another core feature of the role, a feature which is often multilevelled. At the micro level this comprises identifying co-ordinated packages of care for the individual (see Case management 3.4.1.2.iii) and at the macro level it comprises facilitating greater co-operation and liaison between departments and agencies. 'Advocacy' is also seen as major element of the roles ensuring that young people are properly represented in the transition process, helping them realise their needs and maximises their potential, although there could be conflicts of interest between this dimension of the role and delivering a service. In addition there is a 'tracking' role which comprises following young people to ensure that they attend appointments and access services appropriately. This role may be particularly important for vulnerable young

people such as those with HIV or drug abusers. The role may also involve 'outreach' work meeting young people where they are (see Case study 1, The wraparound process).

Case study 1 The wraparound process

The 'wraparound process' refers to a specific set of policies, practices and steps that are used to develop individualised, family-centred services and supports for young people with severe emotional and/or behavioural disorders, and their families. The wraparound process consists of the following key components.

- Wraparound services and supports must be based in the community.

- Services and supports must be individualised to meet the needs of the young people and their families. They should not reflect the needs and priorities of the service system.

- The process must be culturally and socially appropriate, and build upon the values and strengths of the young people and their families.

- Parents must be included in all phases of the process and at all levels of decision making.

- Agencies must have access to flexible, non-categorised funding.

- The process must be implemented on an inter-agency basis and be an integral part of the community in which the young person lives.

- Services must be unconditional. If the needs of the young person and the family change, then the service provision must change to meet those needs.

- Outcomes must be assessed and recorded.

Source: Van Den Berg and Grealish, 1996

Benefits, limitations and application

Supported by a moderate amount of 'evidence' (n = 4 moderately rated evaluative studies), these posts are likely to be beneficial in most settings and may be of particular utility where there are complex needs, vulnerability and multi-service involvement. Transitional workers can be dedicated or the role can be given to a member of the team, as is the case with the specialist nurse. Providing a dedicated worker is costly and it is important that the role is supported by all the agencies involved.

3.4.1.1.ii Transitional teams

Type and volume of items supporting component (theme)

Type of item	Description	Evaluation			Survey/ interviews			Reviews			Total
Strength		S	M	W	S	M	W	S	M	W	
No. of items	11	0	1	4	2	1	4	1	5	1	30
Item codes (referenced in Appendix 8)	7, 8, 13, 19, 23, 25, 32, 41, 48, 49, 51, 52, 54, 56, 57, 61, 65, 73, 75, 76, 83, 84, 93, 104, 113, 115, 117, 118, 121, 125										
Care groups	Diabetes mellitus, cystic fibrosis, physical disability, learning difficulty, congenital heart disease, general disability and chronic illness, HIV positive and at risk street youth, behavioural disorders, complex special needs, rheumatoid disease, visual impairment, survivors of childhood cancer, young people in prison										

Key: S= Strong, M= Moderate, W= Weak – indicating strength of evidence

As with transitional workers, transitional teams come in many forms: there are single and multidisciplinary services, those which are institutionally or clinic based and those which work in the community. The unifying attributes within these roles are very similar to those expressed for transitional workers. Such teams seem to have a particularly important role with young people with disabilities and learning difficulties. There is an important distinction to be made here between multidisciplinary review panels and teams offering therapeutic interventions. The former tend to agree and co-ordinate resources in approving a transitional plan, often to support further educational or employment opportunities, whereas the latter offer continued ongoing care to help young people through the transition period.

Benefits, limitations and application

Again, this component is supported by some evidence (n = 2 moderately rated evaluative studies) and is likely to be beneficial in most settings particularly where multiple or global disabilities are involved; however, providing such a team represents a major investment.

3.4.1.1.iii Transitional services

Type and volume of items supporting component (theme)

Type of item	*Description*	*Evaluation*			*Survey/ interviews*			*Reviews*			*Total*
Strength		S	M	W	S	M	W	S	M	W	
No. of items	3	0	0	3	0	1	2	0	0	1	10
Item codes	13, 25, 45,46, 78, 83, 86, 106, 108, 124										
(referenced in Appendix 8)											
Care groups	Diabetes mellitus, congenital heart disease, learning difficulty, physical disability, chronic illness										

Key: S= Strong, M= Moderate, W= Weak – indicating strength of evidence

Transitional services have evolved mainly because of a growing awareness that young people require a different arrangement for their care from traditional adult and children's services. In health care this has resulted in an emerging sub-speciality, 'adolescent health'. Such services seek to provide continuity in two key ways: firstly, by providing a physical link between services and, secondly, by providing a service which addresses and responds to the emotional and social needs of young people as they develop. These services usually involve clinics or care (inpatient units) facilities, staffed by professionals with specialist knowledge or skills in working with young people. Their focus is often on preparing the young person and sometimes their family for adult life and the responsibility which comes with it, including the care and management of their condition.

Benefits, limitations and application

This approach may be beneficial (n = 2 moderately rated evaluative studies) in providing an important bridge for young people with ongoing needs requiring regular assessment and review. Again, developing such a service would require a major investment so that modification of existing provision to recognise the unique needs of young people may be a cheaper option.

3.4.1.1.iv Developing professional awareness, knowledge & skills

Type and volume of items supporting component (theme)

Type of item	Description	Evaluation			Survey/ interviews			Reviews			Total
		S	M	W	S	M	W	S	M	W	
Strength											
No. of items	5	1	0	2	2	0	2	0	1	2	15
Item codes (referenced in Appendix 8)	25, 42, 51, 52, 57, 62, 73, 74, 80, 82, 102, 108, 110, 118, 119										
Care groups	Cystic fibrosis, general disability and chronic illness, behavioural disorders, complex special needs, survivors of childhood cancer, young people with general health needs										

Key: S= Strong, M= Moderate, W= Weak – indicating strength of evidence

A fundamental component of practice in addressing the transition is the need to equip the professionals responsible for providing care with the ability to recognise, understand and manage the issues in hand. This should include the ability to anticipate and address some of the conflicts inherent within the process, such as the views of parents or carers and the young person. It cannot be assumed that because a person has specialist knowledge of a particular field of care they also possess the necessary skills and knowledge to support a young person through the transition. Therefore, transition training is needed if good transitional care is to be provided and continuity established. Conversely, a lack of staff development has been identified as a barrier to successful transition (see Case study 2 on a programme of education for GPs).

> ## Case study 2 Training programme in principles of adolescent health care for general practitioners
>
> The GP training programme was designed to improve GPs' knowledge and skills in adolescent health, enable them to communicate effectively with young people, screen them for health risk and provide appropriate health promotion. The programme also aimed to improve GPs' attitudes towards young people and increase their understanding of the barriers their practices may pose to young people and how these could be minimised.
>
> The training programme consisted of six weekly sessions that covered the following topics:
>
> * adolescent development, concerns and current morbidities
>
> * understanding the nature of general practice and yourself as a practitioner
>
> * locating other youth health services and understanding how they work
>
> * legal and ethical issues in dealing with young people
>
> * communication and consultation skills and health risk screening
>
> * risk assessment of depression and suicide
>
> * detection and initial management of eating disorders.

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> Additional material included a resource book with reading material expanding on weekly topics, an assessment chart for patient audit, and a logbook for reflection on experience with patients audited. A follow-up session was convened six weeks after completion of the course, for discussion of clinical experiences.

Sanci et al.,*2000*

Benefits, limitations and application

This component is likely to be beneficial for all settings and professional groups and could be conducted across agencies to develop local transitional policies, plans, roles, teams or services. It is relatively inexpensive but would need to be ongoing to ensure sustainability.

3.4.1.1.v Provision of information for professionals

Type and volume of items supporting component (theme)

Type of item	Description	Evaluation			Survey/ interviews			Reviews			Total
Strength		S	M	W	S	M	W	S	M	W	
No. of items	0	0	0	0	0	0	1	0	0	0	1
Item codes	98										
(referenced in Appendix 8)											
Care groups	Physical and mental disability										

Key: S= Strong, M= Moderate, W= Weak – indicating strength of evidence

While this discrete theme was derived from only one descriptive item it does, nevertheless, highlight an important component of continuity practice, namely, the need for information. Given the increasingly fragmented nature of services, a central resource is required detailing the availability of services (including informal networks such as support groups and even materials such as leaflets or videos for young people) to enable the professional to identify and refer or provide the appropriate resources.

Benefits, limitations and application

This component is very weakly supported and its potential benefit to continuity is not established, although it is an inexpensive option.

3.4.1.1.vi Using continuous services to provide bridge (e.g. primary care)

Type and volume of items supporting component (theme)

Type of item	*Description*	*Evaluation*			*Survey/ interviews*			*Reviews*			*Total*
		S	M	W	S	M	W	S	M	W	
Strength											
No. of items	0	0	0	0	0	0	1	0	0	0	1
Item codes (referenced in Appendix 8)	91										
Care groups	Young people with disabilities										

Key: S= Strong, M= Moderate, W= Weak – indicating strength of evidence

The suggestion emerged that continuity can be enhanced by maximising the contribution of continuous services such as primary care. For example, if the general practitioner is providing care on both sides of the transition they could support the young person through that transition. In addition, if more care is located in primary care, supported by specialists, the transition would perhaps be less marked. Thus, while care needs may change, the base from which care is provided would not.

Benefits, limitations and application

This component is very weakly supported and its potential benefit to continuity is not established. However, the evidence from other age groups suggests that primary care can provide equally effective management of many chronic health conditions with specialist providers. The extent to which this could be extended to children and young people is untested because most of these remain within the domain of specialist centres. If child and adolescent provision were to be extended to primary care this would require careful management to ensure that the quality and sensitivity of the provision were not diluted.

3.4.1.1.vii Intra- and inter-organisational (agency) liaison and agreements

Type and volume of items supporting component (theme)

Type of item	*Description*	*Evaluation*			*Survey/ interviews*			*Reviews*			*Total*
		S	M	W	S	M	W	S	M	W	
Strength											
No. of items	13	0	1	3	2	2	7	0	3	2	33
Item codes (referenced in Appendix 8)	1, 12, 13, 18, 19, 23, 32, 36, 38, 41, 49, 51, 52, 56, 57, 61, 65, 73, 75, 76, 82, 83, 87, 91,103, 104, 110, 118, 121, 124, 126										
Care groups	Diabetes mellitus, congenital heart disease, learning difficulties, general disability, HIV and AIDS, complex special needs, rheumatic disease, visual impairment, survivors of childhood cancer, young people in prison.										

Key: S= Strong, M= Moderate, W= Weak – indicating strength of evidence

Clearly, if one of the main problems of continuity is a lack of liaison between organisations and agencies, then mechanisms to promote co-ordination are important to continuity. Inter-agency liaison can be viewed as a continuum that ranges from communication through co-operation to collaboration. Where liaison is seen simply as a matter of maintaining communication between the parties involved in the transition process, this is usually best achieved by appointing a transition co-ordinator who takes responsibility for ensuring information is shared effectively. While communication is needed for co-operation, on its own it does not necessarily result in the inter-agency co-operation which has been identified as an essential component of successful transition planning. A number of transition initiatives involving co-operation between agencies were identified from the literature. In health care provision these included joint outpatient clinics, where paediatric and adult care teams provide care in the same location. The ease of referral and holding of interdisciplinary meetings afforded by these projects is especially useful in promoting good inter-agency liaison, although it has been noted that the commitment of management and staff to the joint venture is equally crucial.

Inter-agency collaboration includes working together as a team, with joint responsibilities and shared decision making. Collaborative approaches to working have been described as essential to developing trust, communication and accountability, and as such are seen as the gold standard for transition programmes. Indeed, this model of service provision actively works to bring down inter-agency boundaries in an attempt to build a cohesive team with the young person and their family as its focus. Contractual obligations may help cement this level of liaison, with service level agreements and continuity planning being built into service contracts.

Benefits, limitations and application

This component is likely to be beneficial in all settings (n = 4 moderately rated evaluative studies). Formal agreements would seem to be essential where complex needs and multi-service provision are involved, if continuity is to be achieved.

Case study 3 Integrated assessment project (IAP)

This project involved the development of a unified assessment process across education, health and social services for children with disabilities at 14+ years, with the involvement of the young person and their family. The initiative worked by bringing the various agencies together in the assessing process which meant that they were each bound into an agreement over what was to be provided by whom over a set time period supported by targets.

The authors suggested that the initiative enhanced co-ordination between services by establishing new patterns and systems for joint working. The IAP was reported to be welcomed by parents although delays had occurred in some specialist assessments and other services were noted.

Source: Partridge and Roiser, 1999

3.4.1.1.viii Organisational planning

Type and volume of items supporting component (theme)

Type of item	Description	Evaluation			Survey/ interviews			Reviews			Total
Strength		S	M	W	S	M	W	S	M	W	
No. of items	1	0	0	0	0	0	2	0	0	1	4
Item codes	18, 87, 85, 100										
(referenced in Appendix 8)											
Care groups	Physical disability, learning difficulties										

Key: S= Strong, M= Moderate, W= Weak – indicating strength of evidence

---

This component of practice is linked to the previous one. It is based on the importance of bringing stakeholders from the various parties together to consider, develop and review practices aimed at improving continuity for a defined group of young people. Inter-agency and professional fora could be advantageous in supporting such a process, together with development of a set of targets or a mission statement to provide a focus for this work. The involvement of young people and families is reported in some of these items.

Benefits, limitations and application

The benefits of this component are not yet established although, again, it seems to be an intuitively useful exercise and one which could provide a firm basis for developing an approach to the transition, which should enhance continuity. However, achieving a consensus may be difficult if services are unable to provide the resources necessary to sustain the same levels of care experienced in childhood. Furthermore, managing the involvement of young people and families in this process will be challenging, although worthwhile.

3.4.1.1.ix Organisational frameworks

Type and volume of items supporting component (theme)

Type of item	*Description*	*Evaluation*			*Survey/ interviews*			*Reviews*			*Total*
Strength		S	M	W	S	M	W	S	M	W	
No. of items	2	0	0	0	0	0	4	0	0	0	1
Item codes	1, 15, 18, 36, 54, 98, 99										
(referenced in Appendix 8)											
Care groups	Physical disability, cystic fibrosis, learning difficulties										
Key: S= Strong, M= Moderate, W= Weak – indicating strength of evidence											

Frameworks to guide practice have been identified as important to continuity. Such frameworks take many forms from clinical guidelines and care pathways to policy initiatives. Some frameworks are derived internally, reflecting local needs, while others are national. At the national level there is an important role for policy and legislation. For example, it is interesting to observe the effect of the 1993 Education Act (Department of Education and Employment (DoEE), 1993) which made the identification of transition plan for children with special educational needs mandatory.

Benefits, limitations and application:

The benefits of service frameworks in promoting continuity are not established, although they should be useful in most settings, providing navigation through the transition and benchmarks for quality.

3.4.1.1.x Accessibility and equity

Type and volume of items supporting component (theme)

Type of item	*Description*	*Evaluation*			*Survey/ interviews*			*Reviews*			*Total*
Strength		S	M	W	S	M	W	S	M	W	
No. of items	3	0	3	2	1	0	2	0	1	0	12
Item codes	15, 42, 51, 55, 57, 60, 62, 85, 88, 104, 115, 126										
(referenced in Appendix 8)											
Care groups	Learning difficulties, physical disability, homeless young people, HIV and AIDS, substance misuse, general health needs										
Key: S= Strong, M= Moderate, W= Weak – indicating strength of evidence											

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This component addresses the importance of equity and accessibility in care continuity. If a service for young people is to reach its client group, then that service needs to be easily identifiable and accessible. It should also ensure that potential inequalities are identified and that young people from different cultural backgrounds, or with health problems or disabilities, are not further disadvantaged through service arrangements.

Benefits, limitations and application

Accessibility was a core feature of some of the most rigorously developed and evaluated items within the review, although tackling inequalities was a more superficial element. Nevertheless, both components are likely to be important to continuity.

3.4.1.2 Process components

Process components are those which identify specific actions aimed at developing continuity in care across the transition. These involve: roles and responsibilities; methods for integration and communication; and the tracking and reinforcement of continuity practices.

3.4.1.2.i Preparation for transition

Type and volume of items supporting component (theme)

Type of item	Description	Evaluation			Survey/ interviews			Reviews			Total
Strength		S	M	W	S	M	W	S	M	W	
No. of items	5	0	0	0	1	2	2	0	2	2	14
Item Codes (referenced in Appendix 8)	28, 42, 43, 68, 73, 76, 78, 79, 94, 96, 113, 114, 119, R36										
Care groups	General disability and chronic illness, behaviour disorders, rheumatoid disease, health care of young people in prison, chronic renal disease, homeless young people, sickle cell disease, physical disability										

Key: S= Strong, M= Moderate, W= Weak – indicating strength of evidence

A number of items identified the importance of preparing for the transition with recommendations including:

- early preparation (at least one year before transfer)

- a visit to the adult clinic or care setting prior to transfer

- adult care arrangements (such as appointments) established prior to discharge

- involvement of the family in preparation for transition

- provision of information, preferably written, about what to expect during and after transfer to adult-based care, including a plan of the adult clinic or care setting and how to find it and the names of the adult-based care team

- opportunity to discuss worries with the children's service provider

Components of practice in the transition from child to adult care

- opportunity to see the children's service provider (i.e. without parents present)

- a period of contact with children's service provider following transfer to adult-based care.

Many of these recommendations are reflected in some of the other components of good practice identified in this section. It is suggested that an adequate period of preparation and the provision of the information outlined above will reduce the anxiety associated with transition for both the young person and their family.

Benefits, limitations and application

While the benefits of early planning are yet to be evaluated, it seems to be something young people and their parents find helpful. Early planning is, therefore, likely to impact particularly on 'experienced continuity' (see Section 1.3).

3.4.1.2.ii Managing the transition process

Type and volume of items supporting component (theme)											
Type of item	*Description*	*Evaluation*			*Survey/ interviews*			*Reviews*			*Total*
Strength		S	M	W	S	M	W	S	M	W	
No. of Items	8	0	0	1	0	1	6	0	0	1	17
Item codes (referenced in Appendix 8)	6, 9, 10, 16, 19, 28, 54, 61, 64, 71, 86, 91, 98, 99, 106, 111,119										
Care groups	Learning difficulties, diabetes mellitus, cystic fibrosis, physical disability, behavioural disorders										
Key: S= Strong, M= Moderate, W= Weak – indicating strength of evidence											

Managing the transitional process can be very complicated depending on the needs of the young person and the number of agencies involved. There is a strong suggestion that a systematic approach may be useful in overcoming such complications. The approach should involve a detailed holistic and individual assessment of the individual, identifying their readiness for the transition, their ongoing care needs and, importantly, their psychosocial development. The assessment should also address the concerns and needs of the family. Assessments may need to be multidisciplinary, depending upon the complexity of the young person's care needs. Following the assessment, a plan should be established setting the goals or milestones for the transition and identifying the resources and support which will enable those goals to be reached. Regular reviews are then necessary to ensure that goals are being achieved, both through the transitional period and then once the transition is completed. While this process of evaluation should be ongoing, it has been suggested that a strategic review point, such as an annual review, may help ensure that progress is monitored effectively.

The young person and their family need to be actively involved in this process. Indeed, the 'wraparound service' identified in Case study 1 uses a goal-setting approach to move young people through transition which is client-centred. This approach encourages the young person and their family to set and evaluate the goals and provides a practical focus for the transition process. It is also suggested that long-term planning is important, developing the basis for effective adult care rather than simply moving the young person from one service to another.

Benefits, limitations and application

This is a well-supported component (n = 2 moderately rated evaluative studies) which is fundamental to the development of an organised approach to managing the transition. Therefore, it is likely to be beneficial to promoting continuity.

3.4.1.2.iii case management

Type and volume of items supporting component (theme)

Type of item	Description	Evaluation			Survey/ interviews			Reviews			Total
		S	M	W	S	M	W	S	M	W	
Strength											
No. of items	2	0	3	2	1	0	0	1	1	0	10
Item codes (referenced in Appendix 8)	42, 55, 60, 61, 62, 115, 118, 122, 125, 126										
Care groups	Behavioural disorders, complex special needs, substance abuse, HIV and AIDS, homeless young people										

Key: S= Strong, M= Moderate, W= Weak – indicating strength of evidence

Case-management approaches were commonly applied to help manage the transition. They were found to be particularly useful in supporting young people with complex needs receiving multi-agency provision. In many ways case management is what transitional workers do, as outlined in Section 3.4.1.1.i. Again, Case study 1, the wraparound service, provides an example of how the case-management model can be used in practice.

Benefits, limitations and application

This component is likely to be beneficial to promoting continuity, particularly if located within the role or methods of an identified transitional worker or team.

3.4.1.2.iv Accountability for process

Type and volume of items supporting component (theme)

Type of item	Description	Evaluation			Survey/ interviews			Reviews			Total
Strength		S	M	W	S	M	W	S	M	W	
No. of items	0	0	0	0	0	0	1	0	0	0	1
Item codes (referenced in Appendix 8)	91										
Care groups	Young people with disabilities										

Key: S= Strong, M= Moderate, W= Weak – indicating strength of evidence

It has been suggested that clear lines of accountability in managing the transitional process are important both for ensuring that goals are achieved and that services fulfil their obligations.

Benefits, limitations and application

The benefits of this component are not established in relation to continuity although, again, establishing lines of accountability would seem to be fundamental to managing the transition process in most settings.

3.4.1.2.v A strong therapeutic relationship

Type and volume of items supporting component (theme)

Type of Item	Description	Evaluation			Survey/ interviews			Reviews			Total
Strength		S	M	W	S	M	W	S	M	W	
No. of items	2	0	0	1	1	0	0	0	0	0	4
Item codes (referenced in Appendix 8)	42, 57, 62, 68										
Care groups	Substance abuse, HIV and AIDS, homeless young people										

Key: S= Strong, M= Moderate, W= Weak – indicating strength of evidence

In programmes which utilise transitional workers there is the opportunity for the one-to-one working which facilitates the development of a therapeutic relationship. When working with vulnerable young people such as those who are HIV positive or involved in substance abuse, building a relationship of trust may be the most important component of the care and services provided. It may be this relationship with the worker that is key to keeping the young person in the programme, or bringing them back after a period of absence.

Benefits, limitations and application

Developing a very strong relationship between the young person and the professional to support care during this often volatile period is likely to be beneficial. particularly for vulnerable or marginalised groups.

3.4.1.2.vi The need for advocacy

Type and volume of items supporting component (theme)

Type of Item	*Description*	*Evaluation*			*Survey/ interviews*			*Reviews*			*Total*
Strength		S	M	W	S	M	W	S	M	W	
No. of items	2	0	1	1	0	0	1	0	1	1	7
Item codes (referenced in Appendix 8)	14, 23, 48, 55, 60, 62, 119										
Care groups	Learning difficulties, substance abuse, HIV-positive and at-risk youth, homeless youth, physical and mental disabilities, chronic illness										

Key: S= Strong, M= Moderate, W= Weak – indicating strength of evidence

As stated earlier, advocacy is seen as one of the key roles of the transitional worker or team, and even in the absence of such a worker it is no less important. Advocacy is important because of the differential power relationships involved between both the young person and the services and the young person and their parents. If an aspect of continuity is about enabling the young person to express and take responsibility for their own needs, then advocacy is an essential element in helping the young person develop the confidence for this. The advocate does not have to be a professional; they can be a representative from a voluntary organisation or a family member or friend. The advocate will work with the individual young person to ensure their views are put forward and that they support any decisions made.

Benefits, limitations and application

This component is likely to be beneficial in most care settings, although there is a potential for conflict where the advocacy role is located in service providers, since their independence may be compromised or perceived to be compromised.

3.4.1.2.vii Joint management of care

Type and volume of items supporting component (theme)

Type of item	Description	Evaluation			Survey/ interviews			Reviews			Total
Strength		S	M	W	S	M	W	S	M	W	
No. of items	3	0	0	1	0	0	2	0	0	1	7
Item codes (referenced in Appendix 8)	13, 25, 37, 80, 106, 110, 120										
Care groups	Diabetes mellitus, cystic fibrosis, congenital heart disease										

Key: S= Strong, M= Moderate, W= Weak – indicating strength of evidence

Joint management of care involves sharing, at some level, the responsibility of care between child and adult services. This may involve sharing expertise, joint assessments, pooling resources or shared provision. Joint care management is undertaken for different reasons and to varying levels in different areas of practice. In some areas involvement is approached on a case-to-case   basis depending on the needs of the young person, while in others it involves shared clinical management through either joint clinics or integrated teams. Case study 4 provides an example of this in relation to congenital heart disease.

Case study 4 Transition clinic

One of the main differences between paediatric and adult health care is that the responsibility for health care is shifted from the parents to the young person themselves. A transition clinic has been established at the Royal Brompton Hospital, London, to help young people with congenital heart disease adapt to this altered responsibility, as well as some of the other changes which accompany this transitional stage of development, such as sexual maturity, concerns about employment, and social relationships.

Key features of the transition clinic include:

• health care provided by a team of professionals which includes paediatric cardiologists, adult cardiologists, cardiac surgeons, nurses and other health care professionals

• care provided on the same site as the paediatric and adult clinics

• weekly clinics

• young person usually referred at 16 years of age

• young person usually attends with parents at first; after a few appointments is then seen alone

• facility to arrange out-of-hours consultations

• encouraged to discuss a range of psychosocial issues as well as health-related concerns.

Source: Anonymous 10

Benefits, limitations and application

This component is likely to be beneficial, particularly in the management of conditions not associated with a life expectancy much beyond childhood, such as cystic fibrosis or congenital heart disease, where much of the medical expertise is concentrated in children's services.

3.4.1.2.viii Flexible point of transfer

Type and volume of items supporting component (theme)

Type of Item	*Description*	*Evaluation*			*Survey/ interviews*			*Reviews*			*Total*
Strength		S	M	W	S	M	W	S	M	W	
No. of items	1	0	1	2	0	1	2	0	1	2	10
Item codes	25, 31, 33, 55, 62, 76, 78, 79, 117, 119										
(referenced in Appendix 8)											
Care groups	Cystic fibrosis, behaviour disorders, rheumatoid disease, physical disability, HIV and AIDS										

Key: S= Strong, M= Moderate, W= Weak – indicating strength of evidence

Flexibility in the entry and exit criteria to child, transitional and adult services has been developed in some care services. This reflects a recognition that chronological age in itself is not sufficient to determine the most appropriate timing of transition, which should instead be based upon other considerations including emotional maturity and health status. A key question here is whether it is safe to transfer the person. Thus an element of the assessment must be to examine the individual's readiness for the transition. One of the identified studies developed a standardised instrument in the form of a questionnaire, measuring variables such as care knowledge to assess readiness for the transition.

Benefits, limitations and application

This component is likely to be beneficial in most settings but it may require more flexible funding and contractual arrangements.

3.4.1.2.ix Specific communication systems and documentation

Type and volume of items supporting component (theme)

Type of item	Description	Evaluation			Survey/ interviews			Reviews			Total
Strength		S	M	W	S	M	W	S	M	W	
No. of items	8	0	1	1	2	0	3	0	3	1	19
Item codes	1, 4, 9, 23, 24,25, 32, 43, 49, 61, 64, 65, 71, 97, 105, 106, 116, 117, 121										
(referenced in Appendix 8)											
Care groups	Learning difficulties, physical disabilities, cystic fibrosis, spina bifida, traumatic brain injury, general disability, behavioural disorders, sickle cell anaemia, renal disease										

Key: S= Strong, M= Moderate, W= Weak – indicating strength of evidence

Many transition programmes utilise specialised documentation to aid the transition process. Documentation may include important clinical or care details, records of needs assessment, goals set, plans of action, summaries of child-based care, and inter-agency agreements. These records then form the basis of information sharing between the services involved in the transition and provide a way of monitoring progress or potential decline following the transition. In some of the health care-based transition schemes a comprehensive medical summary is forwarded to the adult care team by the paediatric clinician prior to transfer. This record provides a detailed medical history of the client to ensure that the knowledge which the children's team has accumulated over a number of years reaches the adult carers to inform appropriate care for the future. This often involves communicating quite complicated details, for example, details of extensive childhood surgery relating to congenital heart disease. In one item the case summary formed the basis for a transition meeting between paediatric and adult clinicians regarding the transfer of care. The audit of young people's views of this model of transition noted that the young people would like a copy of this medical summary, suggesting a need for a greater user involvement and the potential of patient/client-held records (something not identified by the review).

Another aspect of communication not identified within the review was the use of computerised record systems as a means of information sharing. However, in one item the use of a register of young people was shared with the adult provider to help ensure that people were not lost to the system following transition.

Benefits, limitations and application

This component is likely to beneficial to continuity in most areas, but more work is required regarding the use of electronic systems.

3.4.1.2.x Regular review/audit of service in relation to transition

Type and volume of items supporting component (theme)

Type of item	*Description*	*Evaluation*			*Survey/ interviews*			*Reviews*			*Total*
Strength		S	M	W	S	M	W	S	M	W	
No. of items	0	0	0	0	0	0	0	0	0	1	1
Item codes	18										
(referenced in Appendix 8)											
Care groups	Learning difficulties										

Key: S= Strong, M= Moderate, W= Weak – indicating strength of evidence

The regular auditing of services in relation to their management of the transition may highlight shortcomings in the care transition and how they can be addressed.

Benefits, limitations and application

Benefits are not established regarding this component but, again, an established method of quality assurance is probably sound practice.

3.4.1.3 Outcome components

Type and volume of items supporting component (theme)

Type of item	*Description*	*Evaluation*			*Survey/ interviews*			*Reviews*			*Total*
Strength		S	M	W	S	M	W	S	M	W	
No. of items	0	0	0	1	0	0	3	0	0	1	5
Item codes	18, 46, 85, 88, 99										
(referenced in Appendix 8)											
Care groups	Diabetes mellitus, learning difficulties, physical disability										

Key: S= Strong, M= Moderate, W= Weak – indicating strength of evidence

They were very few items which identified outcomes either as part of their evaluations or as aspects of practice. The following list identifies some of the variables contained within items which may be useful to consider.

- Clinical/care outcomes improved or maintained (for example, diabetes control).
- Young person/family satisfaction with their experience of care (are expectations being met?).
- Young person/family knowledge about their condition improves or declines.
- Young person is able to adopt adult roles.
- Young person becomes self-determining in the management of their condition.

It was also observed that examining these outcomes in the longer term may be beneficial.

Benefits, limitations and application

The outcomes identified are context-specific, in that there are no universal measures of continuity (in any of its dimensions) which can measure whether continuity has occurred or not, although those suggested maybe of use in assessing different aspects of continuity, for different groups, following different types of continuity intervention.

3.4.2 Young people

In this domain, components of practice are identified which focus on the young person. The practices within this domain reflect not only the need to involve young people but also their own changing role and needs as they enter adult life. Many of the practices identified here focus on providing young people with the internal and external resources necessary to make that adjustment to adult life.

3.4.2.1 Specific services reflecting the needs of young people

Type and volume of items supporting component (theme)

Type of item	Description	Evaluation			Survey/ interviews			Reviews			Total
Strength		S	M	W	S	M	W	S	M	W	
No. of items	2	0	1	1	0	1	2	0	0	0	7
Item codes (referenced in Appendix 8)	59, 60, 62, 78, 79, 86, 115										
Care Groups	Diabetes mellitus, HIV and AIDS and at-risk youth, homeless young people, chronic illness										

Key: S= Strong, M= Moderate, W= Weak – indicating strength of evidence

Two initiatives had been developed to ensure that services better reflected the life patterns of young people and to encourage their continued participation in care programmes. The need had been identified for flexibility in terms of timing of outpatient clinics, particularly the availability of Saturday or out-of-hours clinics, to reduce the amount of time missed from school, work or leisure activities. Such initiatives are not just about being flexible but also about encouraging the young person to take some responsibility for their own care arrangements where they are able to do so.

Benefits, limitations and application

The benefits of this component for continuity are not established, although evidence from other fields such as teenage pregnancies suggests that tailoring services to young people is beneficial.

3.4.2.2 Development of skills for independence in life and in managing their condition

Type and volume of items supporting component (theme)

Type of item	Description	Evaluation			Survey/ interviews			Reviews			Total
Strength		S	M	W	S	M	W	S	M	W	
No. of items	11	0	1	0	1	1	1	1	2	1	19
Item codes (referenced in Appendix 8)	1, 5, 10, 12, 28, 50, 53, 63, 64, 66, 67, 71, 95, 103, 107, 116, 118, 120, 121										
Care groups	Physical disabilities, learning difficulties, looked-after children, visual impairment, traumatic brain injury										

Key: S= Strong, M= Moderate, W= Weak – indicating strength of evidence

Developing independent living skills is a commonly cited element of transitional care and, as set out in Section 1, personal growth is regarded as a core facet of continuity in transition from child to adult care. This component of practice aims to support the young person in fulfilling what for many are their most important aspirations, namely, to live as independently as possible, to be able to interact appropriately in the local community, to develop relationships, to access employment or further education, and to achieve financial stability. There are many ways in which these skills can be developed from individual and group work to formal employment and educational programmes. There are also instruments which can be used to assess life skills, helping the transitional worker to identify areas of strength and need. An example of this approach is presented in Case study 5 which describes an initiative directed at young people who have suffered traumatic brain injury. Transition programmes that promote independent living skills may start in the safety of the classroom, but there is a recognition that for training to develop further it needs to take place in real-life settings.

The emphasis is on the need for young people to be independent from their family and professional staff as far as possible. This is achieved by encouraging the young person to be responsible for setting goals and monitoring the attainment of those goals. In this programme the promotion of independence and the emotional growth of young people were seen as interlinked and were developed through a functional skills-based approach to transition.

Benefits, limitations and application

This approach is likely to be beneficial, particularly in helping young people with disabilities and learning difficulties through the transition.

Case study 5 The Vocational Assessment Protocol for school to work transition programmes

The Vocational Assessment Protocol (VAP) is a structured, vocationally oriented functional skills inventory which can be used for assessing, and then developing, functional skills and behaviours needed for successful adaptation to the workplace. The VAP comprises a battery of nine rating scales, or profiles, designed to assess vocationally related skills and behaviours specifically for persons with traumatic brain injury (TBI). At least four of these assessments take place in real-life settings outside of the classroom. An 11-step assessment process accompanies the rating profiles, and the process and procedures used to gather the data, along with the data collection tools (the rating scales) make up the assessment 'protocol'.

The VAP has four objectives:

- to identify work skills and strengths on which to focus rehabilitation efforts

- to provide a structure and protocol for examining the most common cognitive, physical and psychosocial factors likely to affect employment and social functioning

- to provide vocational rehabilitation strategies by minimising vocational barriers through the development of compensatory techniques and the use of creative problem solving

- to define vocational barriers in a way that is meaningful to young people, their families and vocational rehabilitation providers.

Source: Thomas and Botterbusch, 1997

3.4.2.3 Development of self-determination and autonomy

Type and volume of items supporting component (theme)

Type of item	Description	Evaluation			Survey/ interviews			Reviews			Total
Strength		S	M	W	S	M	W	S	M	W	
No. of items	4	0	2	0	0	0	1	0	1	1	9
Item Codes	3, 54, 64, 78, 84, 100, 115, 117, 118										
(referenced in Appendix 8)											
Care groups	Diabetes mellitus, cystic fibrosis, learning difficulties, chronic illness, physical disabilities										

Key: S= Strong, M= Moderate, W= Weak – indicating strength of evidence

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Increasing independence and autonomy is a part of the normal transition to adulthood through which all young people pass. This process can be supported by gradually encouraging young people to become more active and take greater responsibility for their care. For example, some of the occupational therapy-based transition programmes identified in the

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review aimed to work with young people to enable them as far as they were able to take a leading role in their own care.

While empowerment is often said to be part of many transitional programmes and practices, it is often unclear what is meant by it or how it is achieved. Empowerment is usually described as the provision of information to enable a person to make decisions concerning their own health care. In one of the identified items, the concept of citizenship as an underlying philosophy for transition models was promoted because it emphasises a respect for human dignity and the rights and responsibilities of the disabled young person as a citizen. Transition models based upon this concept would encourage and support the young person, with the provision of advocates where necessary, to ensure that the young person is central in all transition planning and maintains control over the transition process.

Benefits, limitations and application

While this component needs further assessment to clarify the impact of specific methods for achieving self-determination and effective agency in different settings, addressing these issues is likely to be beneficial to improving continuity.

3.4.2.4 Supported psychosocial development in the transition

Type and volume of items supporting component (theme)

Type of item	Description	Evaluation			Survey/ interviews			Reviews			Total
Strength		S	M	W	S	M	W	S	M	W	
No. of items	2	0	0	1	0	0	0	0	0	0	3
Item codes	54, 62, 63										
(referenced in Appendix 8)											
Care groups	Cystic fibrosis, HIV and AIDS										

Key: S= Strong, M= Moderate, W= Weak – indicating strength of evidence

This theme has strong links with the previous two, since it is about supporting personal growth and development. It recognises the complexities of the young person's world, such as the competing pressures of family life, peers, relationships, the media and education. It is suggested that attention needs to be given to these forces, providing psychological support either through a listening ear or formal counselling, to ensure that they are addressed. In the case of cystic fibrosis, for example, the young person and their family's expectations may be affected by the nature and course of that disorder, either being unrealistic or unnecessarily cautious. Furthermore, the care initiatives themselves must reflect the world in which the young person lives.

Benefits, limitations and application

The benefits of psychosocial development as a mechanism to support young people through the transition and promote continuity are not yet

established. However, this is likely to be an important area and should not be overlooked in programme development.

3.4.2.5 Involvement of young people in organising services

Type and volume of items supporting component (theme)

Type of item	*Description*	*Evaluation*			*Survey/ interviews*			*Reviews*			*Total*
Strength		S	M	W	S	M	W	S	M	W	
No. of items	2	0	2	0	0	0	0	0	0	1	5
Item codes	10, 12, 60, 115, 126										
(referenced in Appendix 8)											
Care groups	Physical disability, care leavers, HIV and AIDS and at-risk youth, homeless young people										

Key: S= Strong, M= Moderate, W= Weak – indicating strength of evidence

Young people have been involved in organising and planning services in the hope that they can help ensure that services address the issues of the young people who are using the service through the transition (see Case study 6).

Case study 6 Calendar for transitions process (making the person and carer(s) central to planning)

Oldham Social Services (UK)

This project was based on the development of a protocol to support transitional planning, with the involvement of the young person being central so that their needs and aspirations were reflected in the planning process. The project was aimed at young people with disabilities and described a framework detailing the responsibilities of the various agencies to the young person and how they might best be involved.

Source: Anonymous 6

Benefits, limitations and application

The benefits of this component are not yet established although, again, it seems to be an intuitively useful exercise and one which could provide a firm basis for developing an approach to the transition which should enhance continuity. Managing the involvement of young people in this process will be challenging, although worthwhile.

3.4.2.6 Peer involvement

Type and volume of items supporting component (theme)

Type of item	Description	Evaluation			Survey/ interviews			Reviews			Total
Strength		S	M	W	S	M	W	S	M	W	
No. of items	1	0	2	1	1	0	0	1	0	0	6
Item codes	47, 60, 62, 115, 125, 126										
(referenced in Appendix 8)											
Care groups	HIV-positive and at-risk youth, homeless young people										

Key: S= Strong, M= Moderate, W= Weak – indicating strength of evidence

Peer involvement was found to be particularly useful in the case of vulnerable young people, such as those with HIV, where peers have been effective in attracting young people and maintaining them in programmes (see Case study 7).

Case study 7 Peer involvement: Seattle YouthCare

Seattle YouthCare is a programme of prevention, intervention and education for HIV-positive, homeless and at-risk youth. Of the project's adolescent staff, almost half have been recruited from the target population. Peer staff are involved in the following components of the YouthCare programme:

• HIV/AIDS prevention education classes

• street outreach, talking to young people about the project and the services it has to offer

• facilitating HIV-positive support groups

• participation in local HIV community projects

• organising social events for HIV-positive young people.

By involving peer youth in programme design and service provision, creative services have been developed which are accessible, accurately reflect the needs of the target population, and are delivered in way that is acceptable to them.

Source: Tenner et al.*, 1998*

When trying to reach a suspicious and reluctant population, as is the case with many of the young people whom these programmes seek to serve, the use of peers, often young people who have been involved in the programme themselves, can be helpful in breaking down barriers and

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reaching out to those in need. Working under supervision, young people can provide information and run advisory groups, help design posters and leaflets with appropriate language and illustrations, and ensure that services are age-appropriate and reflect the youth culture.

Benefits, limitations and application

This is likely to be beneficial in most settings where the nature of the condition or disability does not prevent such a role. However, getting peer involvement and then training and supporting them can be challenging.

3.4.2.7 Support of young people to develop a new relationship with their parents/carers

Type and volume of items supporting component (theme)

Type of item	Description	Evaluation			Survey/ interviews			Reviews			Total
Strength		S	M	W	S	M	W	S	M	W	
No. of items	1	0	1	0	0	0	0	0	0	1	3
Item Codes	25, 63, 84										
(referenced in Appendix 8)											
Care groups	Diabetes mellitus, cystic fibrosis										
Key: S= Strong, M= Moderate, W= Weak – indicating strength of evidence											

Helping young people take a greater responsibility for their illness or disability, as far as they are able, was the objective of some interventions. This acknowledges that continuity in care is about managing or encouraging personal growth. In achieving this, it is necessary to help redefine the relationship of the young person with their parents. This may require either individual counselling or mentorship for the young person or some level of family therapy (see also component 3.4.3.1).

Benefits, limitations and application

This component is likely to be beneficial, particularly where self-management will be essential to the success of care in the long term.

3.4.2.8 Provision of choices

Type and volume of items supporting component (theme)

Type of item	Description	Evaluation			Survey/ interviews			Reviews			Total
Strength		S	M	W	S	M	W	S	M	W	
No. of items	1	0	0	0	0	0	0	0	0	0	1
Item codes (referenced in Appendix 8)	10										
Care groups	Physical disability and learning difficulties										

Key: S= Strong, M= Moderate, W= Weak – indicating strength of evidence

Although only described in one item, the idea of giving choices to young people reflects the opportunities of the wider peer group and acknowledges wider elements of continuity such as encouraging personal growth, responsibility and empowerment. It may also be speculated that if the young person has chosen future care options they may be more likely to continue with them.

Benefits, limitations and application

The benefits to continuity of providing choices to young people are not established and in some areas there may not be any alternatives available

3.4.2.9 Provision of information

Type and volume of items supporting component (theme)

Type of item	Description	Evaluation			Survey/ interviews			Reviews			Total
Strength		S	M	W	S	M	W	S	M	W	
No. of items	4	0	0	0	0	0	2	0	0	1	7
Item codes (referenced in Appendix 8)	10, 12, 18, 21, 78, 85, 98, 120										
Care groups	Congenital heart disease, learning difficulty, physical disability and learning difficulties, care leavers										

Key: S= Strong, M= Moderate, W= Weak – indicating strength of evidence

As noted in Section 3.4.1.2.i, good information is important in preparing young people for the transition. This information should include:

• details of what to expect

• the information which they will need to safely manage their condition

• details of any support which they may expect to receive

- a clear understanding of their role and responsibilities in their care

- a knowledge of any potential challenges and hazards.

The way in which the information is conveyed is also important and a multi-method approach may be most effective. Strategies identified in the review included verbal explanations, videos, leaflets, introduction to support groups and networks, peer support, web sites, and a telephone help-line. It may also be useful to have an identified contact person to whom concerns may be addressed.

Benefits, limitations and application

Providing information about the transition and on future care arrangements is likely to be beneficial components. Based on the review items, and from evidence in other areas such as health promotion, a medium which will appeal to young people (this may involve young people in designing the materials themselves) and addresses any cultural, cognitive or sensory needs is likely to be more effective.

3.4.2.10 Focusing on strengths

Type and volume of items supporting component (theme)

Type of item	Description	Evaluation			Survey/ interviews			Reviews			Total
Strength		S	M	W	S	M	W	S	M	W	
No. of items	1	0	0	1	1	0	0	0	0	0	3
Item codes (referenced in Appendix 8)	61, 116, 118										
Care groups	Traumatic brain injury, behavioural disorders, complex special needs										

Key: S= Strong, M= Moderate, W= Weak – indicating strength of evidence

Whilst most individualised assessments made during the transition process are used to identify needs or areas of weakness, occasionally this focus is reversed and initial assessments are made which identify strengths, abilities and supports. The transition plan builds on these strengths and identifies sources of support to develop a positive transition programme. This change in focus has been used in three areas where, perhaps, there may sometimes appear to be few positive points to draw upon, namely, complex special needs, severe behavioural disorders (the wraparound process) and traumatic brain injury. The underlying philosophy builds on strengths or existing supports (such as family, friends, existing useful services); more positive outcomes can be achieved for individualised services.

Benefits, limitations and application

The benefits of this component to continuity are not established, although it does represents an interesting and important area for further exploration.

3.4.3 Families

In terms of the volume of identified items this was by far the weakest domain. However, it is an important domain because it acknowledges the centrality of families as both the providers and recipients of care. Their role in care provision should not be underestimated and their potential impact on continuity may be either positive or negative.

3.4.3.1 Support for parents and carers in adjusting to change

Type and volume of items supporting component (theme)

Type of item	Description	Evaluation			Survey/ interviews			Reviews			Total
Strength		S	M	W	S	M	W	S	M	W	
No. of items	5	0	1	0	0	1	2	0	0	3	12
Item codes (referenced in Appendix 8)	11, 12, 19, 24, 26, 28, 35, 53, 64, 75, 84, 113										
Care groups	Diabetes mellitus, cystic fibrosis, learning difficulties, general disability and chronic illness, visual impairment, physical disability										

Key: S= Strong, M= Moderate, W= Weak – indicating strength of evidence

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Families of disabled or chronically ill children may develop an over-protectiveness which, while well intentioned, may be detrimental to the child's development and thence to continuity. This may be particularly evident at transition, where the family is required to begin 'letting go' of the young person and allowing them to accept greater responsibility for their care. It is important to support the family through this difficult period, so enabling them to adjust and, in turn, encourage and support the young person through this time of change. Indeed, this difficulty in 'letting go' has been observed in paediatricians who may feel that adult-based care is inappropriate for their patients. The need to accept responsibility and take a more active role in decision making are important components of the transition to adulthood, and young people with disabilities or chronic illness need to develop these skills, as do all young people. The need to take risks and experience failure are seen as key components of the transition to adulthood. The young person is better equipped to cope with independent living by learning how to cope with failure and disappointments. It has also been recognised that excessive caution concerning a disabled young person's life experiences may limit their options for work and impoverish their life. This is a difficult but important issue to consider for all those concerned with a young person's transition. By focusing too narrowly upon the young person's physical or

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emotional safety their life may be unnecessarily constrained. Parental advisors and support groups have been identified as strategies to fulfil this.

Benefits, limitations and application

This was the most important component of practice within this domain and is likely to be beneficial to continuity (although for some additional cautions see component 3.4.2.7).

3.4.3.2 Parental involvement in service planning

Type and volume of items supporting component (theme)

Type of item	*Description*	*Evaluation*			*Survey/ interviews*			*Reviews*			*Total*
Strength		S	M	W	S	M	W	S	M	W	
No. of items	0	0	0	1	0	0	0	0	0	0	1
Item Codes (referenced in Appendix 8)	88										
Care groups	Physical disability, learning difficulties										
Key: S= Strong, M= Moderate, W= Weak – indicating strength of evidence											

Parental representation in identifying how services should ensure continuity through transition has been suggested.

Benefits, limitations and application

The benefits of this component are not established but intuitively parental involvement in the planning process is likely to yield benefits.

3.4.3.3 Family-centred approach

Type and volume of items supporting component (theme)

Type of item	*Description*	*Evaluation*			*Survey/ interviews*			*Reviews*			*Total*
Strength		S	M	W	S	M	W	S	M	W	
No. of items	5	0`	2	2	0	2	1	1	1	3	17
Item codes (referenced in Appendix 8)	2, 23, 24, 26, 28, 32, 58, 61, 64, 67, 72, 75, 77, 88, 105, 118, 121										
Care groups	Physical disability, learning difficulties, general disability and chronic illness, HIV-positive and at-risk street youth, behavioural disorders, complex special needs, rheumatoid disease, visual impairment, obesity, substance abuse										
Key: S= Strong, M= Moderate, W= Weak – indicating strength of evidence											

Many items highlighted the importance and value of family involvement in transition planning and throughout the transition process, particularly because the family has usually had the responsibility for day-to-day care of the young person over many years and clearly has a special relationship with and knowledge of the young person. This transfer of responsibility is made less stressful if the parents are involved in the transition planning with the young person and the professional care team. In some transition programmes the parents and family are encouraged to pass on skills to the young person which they themselves have acquired over the years of providing care, rather than the young person being trained by health care professionals. Family involvement is also important if care is to be provided in a way which complements the family's culture and values, and which is affordable to them. By actively involving the family in transition planning from an early stage it is more likely that an appropriate and acceptable service will be provided. Where a young person has complex special needs it is essential that the young person and their family are central to transition planning if those needs are to be met. For example, in the wraparound service (Case study 1) the young person and their family are included at all stages of the transition process, and no final decisions can be made by the care team without their agreement.

Benefits, limitations and application

A family-centred approach is likely to be beneficial to continuity in all settings; indeed, it was a feature of some of the strongest items identified in the review.

3.4.3.4 Information for families

type and volume of items supporting component (theme)

Type of item	Description	Evaluation			Survey/ interviews			Reviews			Total
Strength		S	M	W	S	M	W	S	M	W	
No. of items	0	0	0	0	0	1	1	0	0	0	2
Item codes (referenced in Appendix 8)	2, 98										
Care groups	Young people with disability										
Key: S= Strong, M= Moderate, W= Weak – indicating strength of evidence											

As with the provision of information to young people, it is important that families receive adequate information to reduce anxiety and augment their contribution to the transition and the continuity of care.

Benefits, limitations and application

The benefits of information giving have been established in health promotion and it is likely that this component will contribute positively to continuity at transition, although further exploration is required before the extent of this is established.

3.5 The evaluative studies

In addressing the issue of the worth of these practices it is useful to examine in more detail the small number of evaluative studies identified by the review. While these studies examined very different aspects of continuity in divergent populations, the studies can be clustered under a number of headings in relation to the type of interventions being utilised. It should be noted, however, that because of the multifaceted nature of these interventions they do not fit neatly under these headings since they also incorporate many of themes identified in the previous sections. Indeed, it would be difficult to say which elements of these interventions contributed to the reported outcomes.

3.5.1 Specific transitional services

A number of the evaluative studies examined specific transitional services and clinics. While the exact nature of these services was divergent, they all aimed to provide a space for young people which was neither wholly child-oriented nor adult-oriented. Diabetes was an area which seemed to favour these types of intervention, with three evaluative studies being identified (Dunning, 1993; Wilson and Greenhalgh, 1999; Orr *et al.*, 1996). The nature of these services was multifaceted; elements included: the active pursuit of non-attendees; holding clinics in the evening; the development of a diabetes register of young people; the integration of adult and paediatric clinical staff; support groups; 'drop-in' and telephone advice. It should be noted, however, that the methods employed to evaluate these initiatives were generally of a poor quality.

- Dunning's (1993) evaluation was based on a snapshot survey with no control group, although for some reason the views of staff were considered as a point of comparison. The outcome measures included a crude (unvalidated) service satisfaction scale and glycated haemoglobin values, although there were no points of comparison against which these measures could be judged. The authors reported that overall there was high level of satisfaction with the clinic (rated weak).

- Wilson and Greenhalgh's (1999) study was an internal evaluation (i.e. conducted by the service themselves) focusing on the primary objective of the services, which was to actively follow up young people to ensure they stayed in touch with services. They reported success in identifying and re-engaging young people previously lost to the service (rated weak).

- Orr *et al.* (1996) reported a prospective cohort study measuring diabetes control in young people (n = 82) attending a transitional diabetes clinic (the details of which were scant). Their primary outcome measure was glycated haemoglobin as a measure of glycaemic control and it was found that glycaemic control was maintained during the transition period, which was judged a measure of success – see Section 4.4.1.1 for further discussion of this study (rated moderate).

3.5.2 Case management

There were two studies which evaluated the impact of case management.

- Hymel and Greenberg (1998) evaluated a case management programme for young people with HIV and AIDS. The programme involved the use of case managers to co-ordinate care to provide a 'continuum' of services based on an assessment of the medical and psychological needs of the individual. The project was evaluated (internally) using a longitudinal cohort study of young people (n = 14) in the programme, based on in-depth interviews. The evaluators reported improvements in: the young person's overall perception of their life, and their ability to get on with other people and relations with their families. With direct relevance to continuity, the authors report a high degree of usage of health and psychological support services by young people in the programme (rated weak).

- Godley *et al.* (1994) examined a case-management programme for substance abusers, using a before-and-after evaluation (with non-equivalent control). They reported a high level of adherence to the programme with the result that offending and drug taking reduced. They also reported that there was a 37% improvement in the number of young people staying in contact with other services, with other reported benefits being: the encouragement of family involvement in the young person's recovery; connecting the young person with school, work, and community resources; and helping the young person to fulfil legal obligations (rated moderate).

3.5.3 Joint care management – professional transition

Joint care management also featured in the evaluative studies with a focus on the rotation of staff between services.

- Nasr *et al.* (1992) evaluated a transition programme for young people with cystic fibrosis in which 'pulmonary fellows' (junior adult physicians) are matched with patients in paediatric settings for a year prior to their transfer to adult services, with the pulmonary fellow following the patient through for a further year in the adult care setting – providing continuity. The evaluation was based on a survey of users' experience (n = 40) with thirteen of the sample having gone through the transition programme, although the evaluators did not use the opportunity to compare those

experiences, 43% (n = 17) of patients said they would recommend the transition programme (weak method).

3.5.4 Professional development

One study presented an evaluation of a professional development programme.

- Sanci *et al.* (2000) evaluated a GP education programme which aimed to foster a greater appreciation of adolescent care issues, using a randomised controlled trial. The details of this intervention are presented in Case study 2. This was the only study rated as having a strong method. The study assessed the impact of a health training programme for GPs (n = 108) on adolescent health issues. That impact was assessed via a range of outcome measures which included: patient satisfaction and rapport; confidentiality; observer competence; risk assessment; and knowledge and skill. These outcomes were assessed using questionnaires and the analysis of videos of consultations. All the outcomes showed a significant improvement at 7 months compared to the control group, with the exception of patient rapport and satisfaction, which showed no significant change. The author also followed-up the GPs at 13 months and found the impact to be sustained.

3.5.5 Services to develop young people.

Three evaluative studies reported on initiatives aimed at developing young people to be able to maximise their potential in relation to their condition or circumstances during the transition period.

- Hyde *et al.* (1996) undertook an internal evaluation of the 'wraparound' service described in Case study 1. The study surveyed service users (n = 106), young people with behavioural problems, measuring attributes such as community adjustment and satisfaction using non-standardised or validated instruments. They reported that youth and parent satisfaction was high and that most participants had achieved a good community adjustment. It should be noted however that the response rate was poor (rated weak).

- Posthill and Roffman (1991) reported an 'internal evaluation' of a training programme for people with learning disabilities based on interviews and questionnaires with people who had completed the programme (n = 45), although a number of programme 'graduates' declined to participate (n = 26). The study suggested that participants were holding down jobs and living independently, which they in part attributed to their exposure to the programme (rated weak).

- Partridge and Roiser (1999) undertook an internal evaluation of a multidisciplinary assessment programme which was based on a partnership with professionals and young people with disabilities to help them plan for their future. The sampling and methods employed

> in this study were vague and no clear outcomes were reported (rated weak).

- Steele and O'Keefe (2001) provided a before-and-after study (with non-equivalent control) of a multi-agency programme to support homeless young people (n = 106). The aim of the programme was to address issues like drug dependence, health care and employment. The study reported that:
  – drug dependency dropped from 41% to just 3%
  – sexually transmitted disease fell from 60% to 7%
  – 59% completed a hepatitis B programme
  – 42% achieved employment.

3.5.4 Peer involvement

One evaluative study examined a programme in which an important component was peer involvement.

- Woods *et al.* (1998) provided a detailed account of a multi-agency programme for young people with HIV and AIDS, a key element of which was peer involvement. Peers were used to undertake counselling and mentoring under the supervision of professionals. The evaluation was based on a retrospective analysis of service use. The evaluation suggested that peer involvement was important in the programme's success, particularly in engaging young people previously lost to services. This study also provides a good illustration of the multifaceted nature of these interventions because, while peer involvement was a core element, the programme also involved: risk reduction counselling, peer and professional; access to HIV counselling and diagnostic testing; life management and personal development counselling; health screening; follow-up and outreach to ensure continuing care; and multi-agency care co-ordination.

The implications and limitations of these evaluative studies are discussed further in Section 4.4.1.1.

4 Discussion

The review has identified a large number of practice components which may help promote continuity in the transition from child to adult care. While the evidence supporting these components is variable and generally weak, each has the potential to impact positively on continuity. However, simply identifying these practices is not enough, because there will be important variations in their appropriateness and practical application between care groups, services and practice areas. There are also significant differences in the focus and nature of some the identified practice components. While it is intended that the utility of these practices be determined by practitioners in their varied settings, it may be useful to provide some more detailed direction as to how the application of these components may promote continuity.

Thus, in this section of the review some of the core principles common to many of the review items are examined, from which a framework to guide service commissioners and providers in addressing continuity in the transition from child to adult care has been constructed. In addition, some of the underlying dynamic properties of the identified practices are considered with the aim of constructing models of continuity promotion which may have greater application in different care settings. The section concludes by exploring some of the limitations of the review and areas for future development.

4.1 Continuity in the transition from child to adult services

Before discussing how the findings of the review can inform good practice, it is useful to consider what those findings indicate about the nature of continuity in the transition from child to adult services. The range of practices identified in this review supports the multidimensional and 'relational' nature of continuity expressed in the NCCSDO's definitions of continuity (see Section 2.6) (Freeman *et al.*, 2000). However, it is also clear that there is something more to continuity during this transition than is expressed in those definitions, reflecting the enormous developmental process which is occurring during this period and the profound physiological, psychological and social changes which it initiates. This presents practitioners with a paradox, namely, while these changes cause instability they are also part of the normal and healthy process which marks the adoption of new life roles. Thus, a new category of continuity is proposed, to add to the list developed by the NCCSDO (see Section 2.3) – *developmental continuity*, care which not only grows with the changing demands of the client group but also works to facilitate that change. This is distinct from 'flexible continuity' because of the accelerated and predetermined nature of this particular epiphany and because continuity is not just about responding to this change but its active facilitation, encouragement and management. In other words,

the process of change is intrinsic to the experience of continuity and not simply the cause of discontinuity. This definition of continuity is strongly reflected in the framework and models described.

4.2 A framework for addressing continuity planning

While the items identified in the review were derived from different contexts, there were some core principles common to many. These principles related the mechanisms through which the practices had evolved and were sustained. These principles have been organised into a service development cycle comprising seven stages, which may be considered by organisations seeking to better manage the transition from child to adult care (see Figure 4.1).

Figure 4.1 A framework for service development
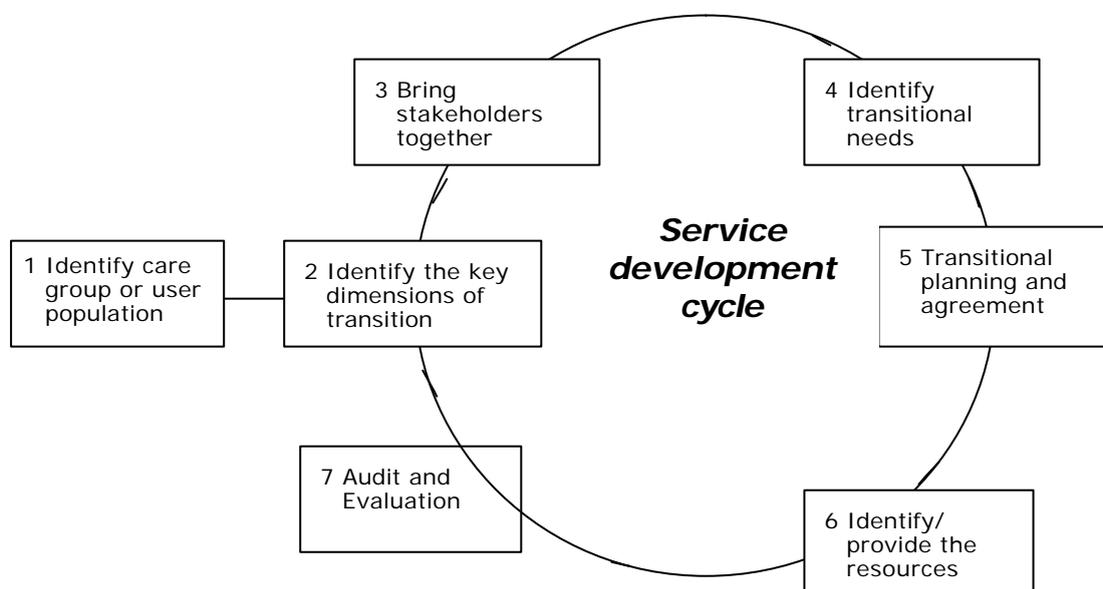
However, it is stressed that this process is derivative, since the principles were not always described explicitly. Many of the principles were implicit in the actions involved in, or proposed by the item, because very few contained clear statements regarding their antecedents, context, development and implementation (including who and what were involved). Thus, some caution is introduced as the proposed framework is derived from 'latent' rather than 'manifest' practices. Indeed, given the paucity of the primary materials available to the review, the framework should be regarded as highly tentative and in need of more in-depth exploration and development. The seven stages of the process are as follows.

1   *Identifying the care group or user population.* It is useful to begin with a clear construction of the user population. However, caution should be exercised for fear of wrongly assuming that people with a

shared condition are homogeneous. For example, there may be young people with a disability for whom self-directed care is possible while others may require continuous support. They may also be people from different minority groups within the user population facing very different issues. In addition, considering the limitations of chronological age highlighted in the review and the need for flexibility in determining point of transition, it may be necessary to develop criteria defining the point at which the transition begins and ends. Such criteria need not be fixed by age but based upon an assessment of readiness and progress.

2   *Identifying the key dimensions of the transition.* This is perhaps the most important aspect in ensuring continuity through the transition because it is fundamental to the type of initiatives employed. In doing this it is important to recognise that the transition is multidimensional, involving aspects within the young person (for example, their own personal growth and development), the family (for example, the process of 'letting go') and the service (for example, communication and agreement between and within agencies). These dimensions should also be viewed interactively. For example, if a new system for transferring paediatric diabetes records to adult services were developed it may not have any impact on clinical outcomes if simultaneous efforts are not made to help the young person identify their self-care responsibility for their condition. It is also useful to consider how the NCCSDO definitions of continuity and developmental continuity may impact on each of the identified dimensions (see Section 2.3). Even if some aspects of the transition are ignored to permit concentration on one or two areas, it is still useful to be clear about all the dimensions, for these may be important to understanding the success or failure of any intervention.

3   *Involving stakeholders.* Given the multidimensional nature of continuity during transition, many different professionals and service groups should be represented, together with young people and their families. Stakeholder involvement should be ongoing and should be reflected throughout the developmental, implementation and review of initiatives. Clearly, this will require a commitment to the process and the resources to sustain that involvement. A working party might be one strategy, thereby providing a group to consult with as many service users and providers as is feasible.

4   *Identifying transitional needs for each dimension of the transition.* Once the various dimensions of continuity have been agreed, the task is to examine the issues surrounding each dimension, addressing questions regarding what hinders or impedes continuity and what services or aspects of provision within services are involved. This process should ideally run in parallel with the previous stage and the involvement of stakeholders.

5   *Transitional planning at the individual, organisational and inter-organisational levels.* This stage involves different levels of planning.

While the individual plan is central, it is important that appropriate structural arrangements are in place to support that plan and hence the need for intra- and inter-service planning.

6   T*he provision of the appropriate resources to support the transitional plans.* To make plans in isolation of the resources to support them is obviously not worthwhile. The challenge here is that the necessary resources are unlikely to be in the gift of one organisation.

7   *The evaluation of the transition at each proposed level.* The evaluation or audit of the transition must consider all the dimensions of continuity identified in Stage 2. It may be useful to consider a range of outcomes in undertaking the evaluation appropriate to each dimension of continuity (see Section 3.4.1.3). Again, this should ideally involve stakeholders.

It is hoped that this framework may be useful in helping managers and practitioners operationalise some of the policy initiatives identified in Section 1.3.

4.3 Models of continuity promotion

When consideration is given to the underlying dynamics of the various practices identified in the previous section, some interesting patterns emerge. These patterns reflect the different foci of the initiatives described within the review items, particularly in the way in which young people and the transition itself were viewed. In some initiatives the focus was on getting the young person from child to adult services as safely and efficiently as possible; in others, a more developmental model was adopted, seeing the transition within the context of personal growth. In these latter cases continuity was established by equipping the young person with the resources necessary not only to weather the transition but to take on a new role in relation to their condition or disability. In examining these patterns four models for continuity promotion in the transition from child to adult services have been identified.

Model 1: Direct transition

In this model continuity is achieved when the young person is transferred to adult care safely and efficiently. The emphasis is on structural factors such as good channels of communication and information sharing. The focus is primarily on relations between services, and addresses *continuity of information* and *cross-boundary and team continuity*. Such structures need to be considered horizontally (between multiple services within each age-band structure) as well vertically (from child to adult). The model is illustrated schematically in Figure 4.2.

Figure 4.2 Direct transition model
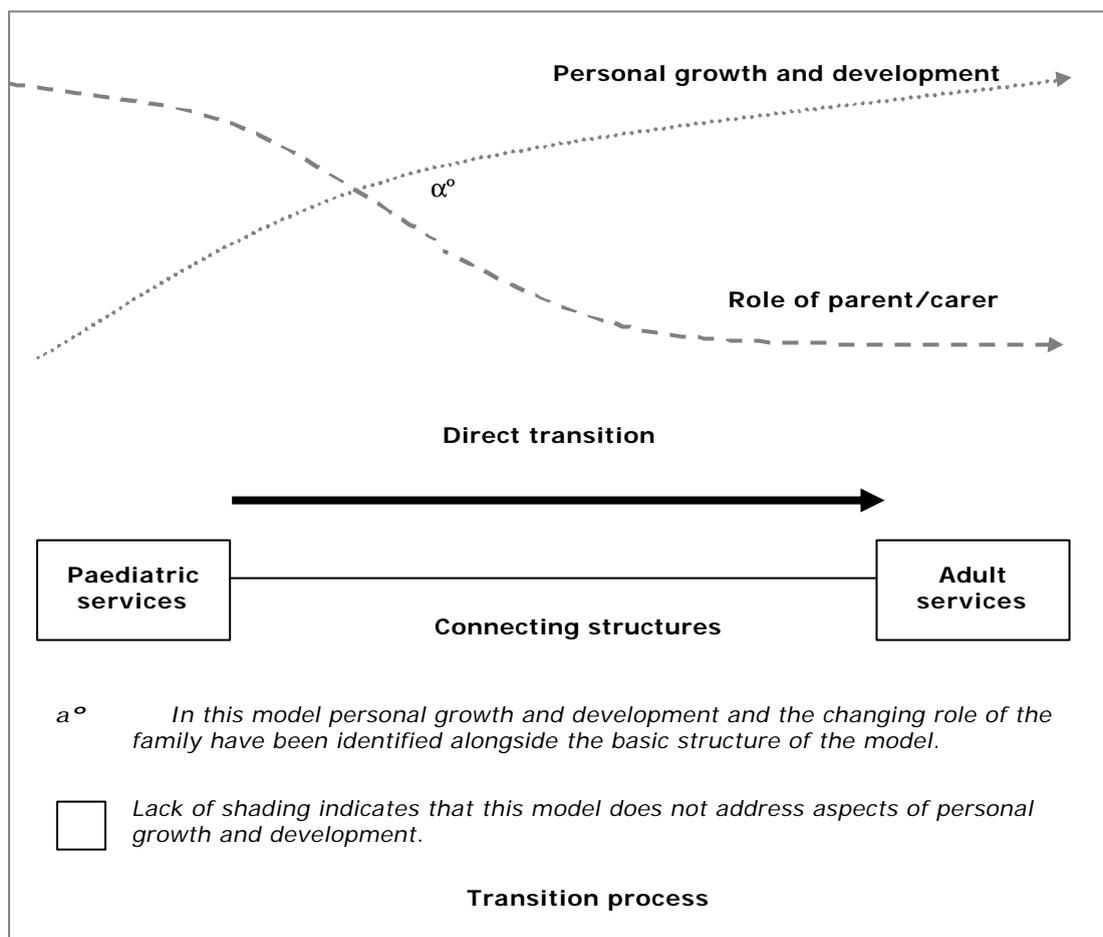
This is to reinforce the point that these factors exist independently, whether or not they are addressed directly by the continuity-promoting practices employed. It is also important to note that there will be variations in the degree and velocity of change attached to these factors; particular consideration needs to be given to the impact of the disease or disability on the developmental potential of individual. These factors are applicable to all the models, although as illustrated in Figure 4.2 they are not the primary focus of this model. This approach is probably adequate where the disease or disability has minimal impact on the young person's ability to develop naturally using existing resources and support systems to manage in an adult care environment. It may also be appropriate where the young person's role in their care provision is unlikely to change significantly.

Model 2: Sequential transition

In this model, services and care are constructed recognising that the young person's needs are changing and that they require some preparation if they are to adjust to adult care successfully. Such

services are either constructed as an extension of child provision or jointly between adult and child providers. The model is illustrated schematically in Figure 4.3.

Figure 4.3 Sequential transition model

a°   *In this model the rate and potential for development can vary, impacting on the potential of the young person and the role of the family or carer.*

Graduated shading is used to illustrate that this model includes the potential to address some aspects of personal growth and development.
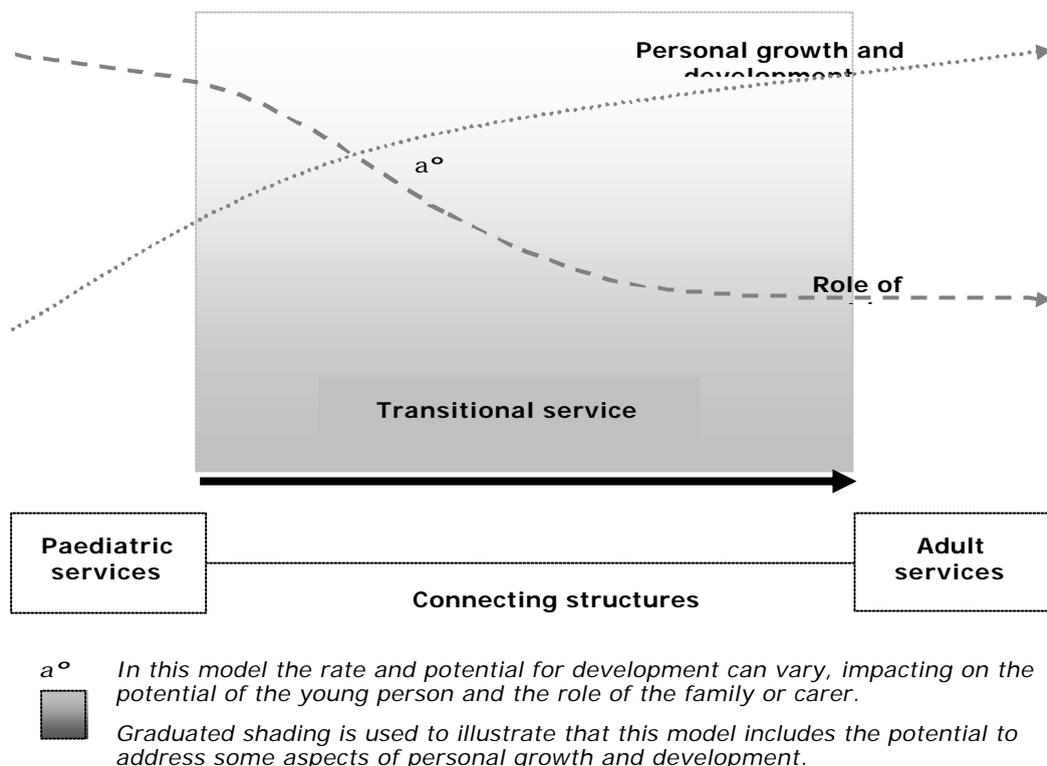
Transition process

In this model *flexible* and *longitudinal continuity* are addressed. This sequential model is particularly important when the young person's role and responsibilities for their care are likely to change significantly. The service structure and care should be distinct from child-orientated care and allow the young person to rehearse and prepare for adult-based care. Where possible, the aim should be to assist the young person in becoming an 'expert' with regard to their condition. This may involve an important redefining of the family role with the young person being given increased autonomy in making decisions about their care. They may, for example, start attending appointments on their own. Clearly, this process requires facilitation and professional transitional roles need consideration.

Model 3: Developmental transition

This model starts from the premise that the young person will need some help in acquiring the skills and support systems necessary to use or experience adult care effectively. The model is illustrated schematically in Figure 4.4.

Figure 4.4 Developmental transition model

a° *In this model the rate and potential for development can vary although it is likely that these young people will need active assistance in supporting their personal growth and development.*
Solid shading is used to illustrate that this model fully encompasses personal growth and development.
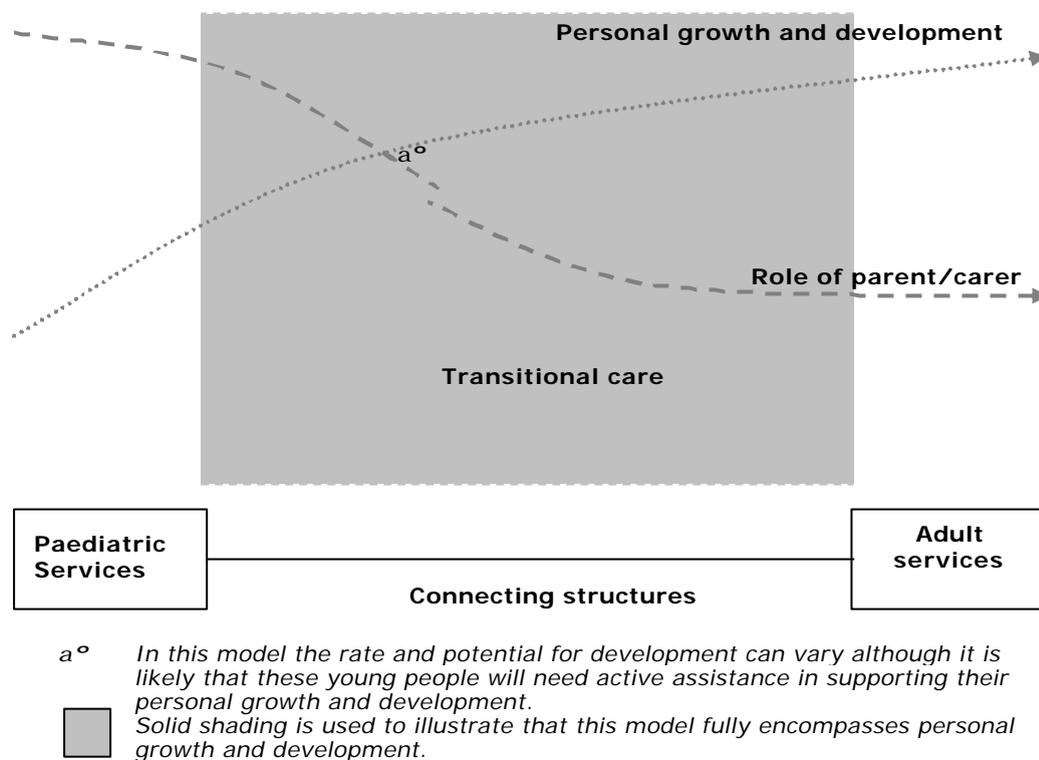
Transition process

This model has some affinity with the previous model, but is distinct with an active focus on personal growth and development with the transition, *developmental continuity*. Again this is likely to involve a redefining of the family's role in care provision. In keeping with the model's focus, the transitional care box within the model extends to encompass personal development and the family's role. This model is likely to be particularly useful for vulnerable young people and those with physical disabilities or learning difficulties.

Model 4: Professional transition

This final model is very distinct from the other models as its focus is not directly on the young person. In this model the professional responds to the young person's needs to release the concentration of expertise from within one service type (adult or child) and to develop *relational* or *personal continuity*. This model may be particularly important in conditions with a short life expectancy or where expertise is heavily located in one service, for example, cystic fibrosis or HIV and AIDS. The model is illustrated schematically in Figure 4.5.

Figure 4.5 Professional transition model
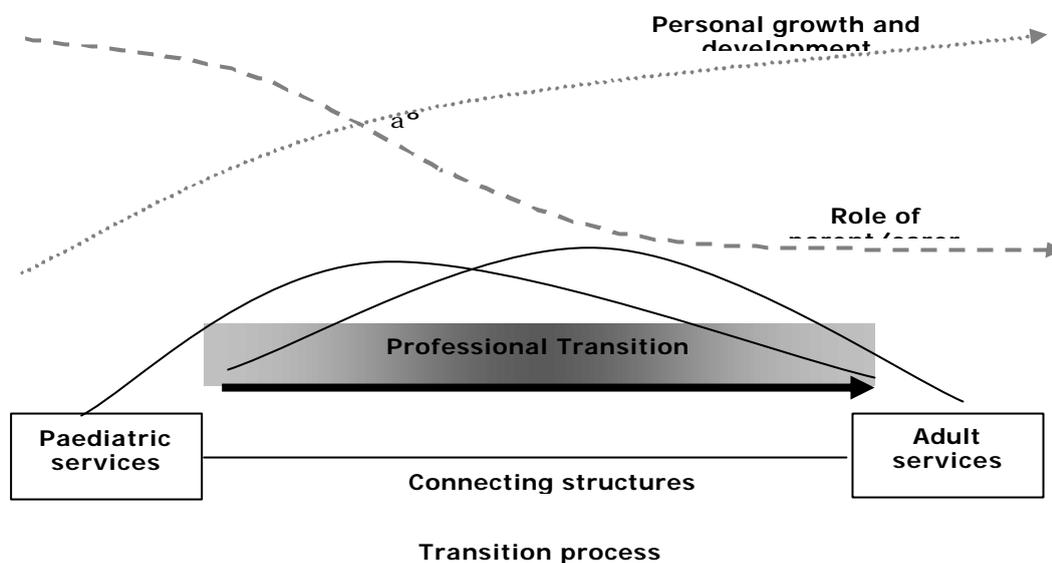
It is stressed that these models are not mutually exclusive and that in many circumstances more than one model could be utilised. For example, a sequential–developmental transitional model, in which the space for personal growth and the support to achieve it are applied in union. Indeed, the different dimensions of continuity identified within these models will always apply to varying degrees. The question in deciding upon the most appropriate approach to service delivery is which of these dimensions (if not all) are most important to the transition under consideration. The models can be identified along two continua:

1   the focus continuum – young person to service

2   the developmental process continuum – implicit to explicit.

Considering where on these continua the transitional needs of a given group of young people are best addressed should be a key factor in determining the approach. In the light of the limited evidence, interactive application of these models may be the most productive.

4.4 Limitations of the review

The findings and theoretical constructions derived from this review must be considered alongside some of the methodological limitations and practical constraints of the review.

4.4.1 Limitations with primary materials

The most significant limitation of the review relates to the primary materials (research and practice) available for analysis. The aim of the review was to identify 'good' practice in the transition from child to adult care. To achieve this, and to ensure a comprehensive account, it was

envisaged that a broad range of materials addressing various aspects of the transition would be required. It was also recognised that a responsive approach to attributing the worth of this material in relation to the transition would be needed, for example, by giving equal weighting to quantitative and qualitative material. Adopting too narrow a focus on what constituted worthy evidence – such as the hierarchical model favoured by traditional evidence-based practice methods such as systematic review, with its bias toward randomised controlled-trials (RCTs) – would not have allowed the review to report such a diverse range of practices. Indeed, had such a method been adopted the conclusion of the review would have been short, reporting that there is no good practice in relation to the transition from child to adult care. This reveals one of the key epistemological weaknesses of that approach. Furthermore, the systematic review endeavours to establish homogeneity in the target population, in the interventions and in the outcome measures examined, factors at odds with a topic like continuity which is inherently multifaceted and with the review's heterogeneous target populations.

However, it must be acknowledged that while many items contained rich description and a degree of theoretical sophistication, most lacked the rigour and depth of analysis necessary for a more objective assignation of their worth. What the review was looking for were studies or projects which indicated what differences occurred and, more importantly, what it was that made those differences. It was hoped that, even if those foci were not explicitly addressed within the material, it would be possible to identify them to some level by examining the structure, process and outcomes of each item. While this was achieved to some extent, much of the material was simply descriptive and reported limited details of process or outcome so that there was insufficient to support a rigorous analysis. In addition, none of the studies reported long-term follow-up, something which is clearly essential to understanding the impact of an initiative across the transition. These shortcomings probably reflect a lack of resources for the evaluation of these initiatives. Thus, the extent to which the practices described in this review were good is difficult to determine with any degree of certainty.

There are, however, alternative ways of viewing whether a particular practice is good or not. This review has sought to extrapolate core facets of practice from a wide variety of sources across contexts. These facets are more than simple descriptions since they represent the mechanisms through which current practices operate, as illustrated by the framework and models described. In 'realist' policy evaluation terms, these are referred to as generative mechanisms (Pawson and Tilley, 1997). At this level, the question of whether these mechanisms are good or bad is inapplicable, because this question only has meaning when the mechanisms are applied in a given context. Thus, it could be argued that all these mechanisms have the potential to impact positively on the different dimensions of continuity. The mechanisms represent good practice:

- in the first instance, if they are judged to be of use by those involved in establishing continuity for a particular group of young people

- in the second, if they lead to some improvement in a given set of continuity dimensions.

This latter claim can only be confirmed following rigorous evaluation. In addition, in considering these mechanisms it is important to consider other extraneous factors such as the provision of the resources necessary to trigger and support the action potential of those mechanisms. Therefore, it can be said that the review has identified potential mechanisms for good practice in addressing continuity in the care transition across a range of settings. In these terms the aim of the review has been accomplished, although it is emphasised that there may be other mechanisms which the review did not identify.

4.4.1.1 The evaluative literature and outcome measurement

It is useful to make some additional observations regarding the evaluative studies that were identified in the review, and to discuss more fully the issue of outcome measurement in relation to continuity.

The evaluative studies examined within this review were generally of poor methodological quality. The principal problems with these studies stemmed from the fact that many were 'internal' evaluations without any equivalent control or comparison groups. Not only is the internal validity of these studies questionable, but also the extent to which they contribute 'direct' knowledge of what works in promoting continuity, since the examination of continuity within these studies is an implicit rather than explicit objective. Indeed, the only study which was found to have a strong method (Sanci *et al.*, 2000 – study 102 in Appendix 8) was limited because it was conducted in a short time frame, so that the benefits of this training programme may not have been long-lived, although the authors did suggest that the improvements were still evident at the 13-month follow-up. In addition, the connection between this intervention (which aimed to increase GP awareness of young people's needs) and the experience of continuity is unestablished; thus it is contestable whether improving GP awareness necessarily equates to improved continuity. Clearly, the strongest designs for assessing continuity will need to be longitudinal, with frequent measurement of continuity-specific variables, and ideally with some comparison groups.

This observation leads to the issue of measurement. In the absence of any standardised outcome measures for continuity there is a necessary reliance on proxy or internally generated measurement. Indeed, the production of a standardised measure would be problematic given the multidimensional nature of continuity and its varied expression within different populations. Thus, great care needs to be used in ensuring that the appropriate outcome measures are utilised. In terms of health care it is important to recognise that while clinical outcomes are important they should not be the only consideration. For example, consider study by the

Orr *et al.* (1996 – study 84 in Appendix 8). In this study a key measure of glycaemic control (HbA1c) was shown to have shown no significant improvement. One reading of this may be that the intervention (an adolescent diabetes unit) was ineffective; however, against a background of 'teenage troubles' this was reported as a positive outcome in that their glycaemic control did not deteriorate during this period, which is often the case, although a comparison or control group may have illustrated this more convincingly. What the study did not measure, however, were other attributes which might have given this finding more meaning such as 'locus of control' or 'diabetes quality of life' for which there are a number of well-validated measures. This example also emphasises the need for caution in interpreting outcomes, because there may be contradictions in their presentation which if naively interpreted could prejudice the case for a given intervention. The continuity framework described in Section 4.2 may be useful here because it stresses the importance of making explicit the population and dimensions of continuity to be addressed. While many measures will need to be internal to the nature and focus of the programme and the elements of continuity being addressed, the inclusion of some generic measurement would be useful if studies are to contribute to the understanding of continuity management generally. Indeed the development of an item or instrument bank which such studies could draw on would be advantageous.

The models described in Section 4.3 may also facilitate such decisions, recognising that the outcomes of interest will vary depending on which model is applied. For example, in the developmental transition model measures of personal growth and development (these include sense of coherence, self-esteem, locus of control) may be more informative than measures of disease or health outcome in isolation. Conversely, in the direct transition model health outcome measurement or service satisfaction measures may be more informative. It may also be useful to include measures of 'carer burden' where the family role is important.

Furthermore, given the inherent complexity of this topic, it is cautioned that examining outcomes in isolation of the context of the programme and the processes involved within it may be flawed. Indeed, in many ways continuity is about process (reflected in the large volume of material describing process found in this review) and while the process must aim to produce an overall benefit (an outcome), measuring the quality of the process must be intrinsic to any evaluation of continuity. For example, in the study by Godley *et al.* (1994 – study 55 in Appendix 8) one of the key measures within the study was whether the young people stayed in the programme (substance abuse) and the frequency of contact with the case managers operating the programme. Clearly, knowing that these young people were supported through time by the programme in itself suggests continuity and contributes to the interpretation of the outcomes which were reported to be positive.

4.4.2 Limitations with the scope of the review

The reader is also reminded of the scope of the review as described in Section 1.4 and in particular the focus on explicit practices. In undertaking this review it is clear that there is still much to be understood in relation to what helps young people adjust to adult care settings. Missing are more in-depth accounts of what is actually said and done in the process of enacting the initiative within a given context. There is a tendency to focus on the 'special role' or the 'special facility' (descriptions of structure) without really describing the care approach employed. For example, while providing a specialist nurse to work across the transition can be shown to improve continuity across services, this does not tell us why or how that improvement is gained. Referring back to some of the roles of transitional workers described in the previous section (such as co-ordination, planning, advocacy, policing, etc.), it would be useful to know which of these roles was dominant in the post or, if all were active, how the different role facets impacted on the identified dimensions of continuity. Furthermore, it would be useful to tease out within that examination the different experiences of the service, the young people and the family. It is insufficient to say 'here is the initiative and here are the outcomes', as invariably these initiatives are multifaceted. Clearly, if a greater understanding of what is important in the transition is to be achieved, a new approach to examining the processes involved in managing that transition successfully needs to be employed. A key aspect of this approach must be to explore in a more organised manner the mechanisms through which the initiative impacts on the different types of continuity and to examine some of the more implicit elements within that process.

Another important issue relating to the focus of this review is the extent to which the promotion of continuity can be examined across such a broad range of service types and population groups. This question is particularly acute when viewing health and social care in union. Consider, for example, the fundamental difference between the medical and social models of disability. There are two dilemmas to consider:

- firstly, to what extent can materials derived from such diverse sources be meaningfully integrated?

- secondly, do the products of such an analysis have any meaning when taken back to those sources?

Regarding the first dilemma, trying to assimilate the broad spectrum of different materials has certainly been challenging. Distinctions between health and social care items were observed. In general terms: the social care items tended to be very multidimensional and policy-oriented with a strong focus on developing the young person (developmental transition), while health items tended to be service-oriented, describing services tailored to young people with particular health needs (transitional and sequential transition) – allthough certain groups, most notably occupational therapists, seemed to straddle both camps. There were also significant differences in methodological approaches, with health service

items generally being more rigorously evaluated than social care items, which tended to be more descriptive. This may reflect both the greater research funds available to support health services research and the current emphasis upon evidence-based practice, while social care has always been heavily influenced by policy. Nevertheless, it was possible to examine these distinct types of items in union although, as one might expect, the contributions to the various models were somewhat polarised along the lines of the distinctions described above.

Regarding the second dilemma, the extent to which these models will have meaning when returned to the original settings, the jury is still out, as this will need to be tested in practice. It is hoped, however, that the synthesis of these different materials will not result in a 'dumbing down' of practices but will rather bring about cross-fertilisation. Perhaps this will give added value by introducing practitioners from across the spectrum to new ways of looking at, and managing, continuity.

4.4.3 Methodological limitations of the review

Finally, there are also a number of methodological constraints which must be considered.

Completeness

Firstly, there is the issue of completeness, the extent to which the review identified sufficient materials to support the analysis. In terms of the literature searches, a particular weakness was the failure to pursue secondary references consistently. Therefore, it is possible that some relevant studies were missed. Another factor which may have contributed to a potential lack of completeness were the search terms. These terms were difficult to define because of the recalcitrant nature of the concepts being examined. External validation of these terms would have been advantageous, although the research team contained extensive expertise. Also, because the review was in part directed by tracer conditions, detailed in Section 2, there may have been bias in the type of materials identified. However, while the issue of completeness is unresolved, it is contended that given the huge volume of material identified sufficient data were secured to support the level of analysis undertaken. Thus, although it is likely that there will be a number of specific practices which were not identified, whether these would have generated other models or have amended those already proposed is unknown.

In terms of the survey, the heavy reliance on pre-set questions to facilitate ease of completion and analysis may have restricted the ability of respondents to fully express and relate aspects of continuity management in their practice. The survey instrument was again biased towards the tracer conditions. In addition, following up survey respondents for a fuller account of their practice would have added material for the analysis but unfortunately time constraints precluded

this. It should also be remembered that this was not a nationwide survey.

Materials analysis

Secondly, there are a couple of weaknesses with the analysis of the materials. The coding schedule, once developed, was not reapplied to the data. It is important to do this not only to check the validity and reliability of the schedule but also to control for the identification of further practice items. There is also an issue with the way that practices were coded as strong, moderate or weak. The focus of this grading was at the methodological level and not at the practice component level. Thus, as many items related multiple practices, there is no allowance made for the fact that some of these practices may have been peripheral to, or even unaddressed by the method. If the method was strong, the practice component was reported as strong. The reason for this reflects that outcomes and the direction of impact (the degree of change positive or negative in continuity of care) were not consistently accounted for, so that grading items consistently beyond the quality of the method was not possible.

Review

Thirdly, the external validity of the identified components of practice, framework and models would have been enhanced had they been reviewed by stakeholders, including practitioners and young people.

5 Recommendations

The review has highlighted a number of key components of practice which focus upon the service and the user perspective (young person and parents/carers/families). Enabling service components were identified regarding structure, process and, to a limited extent, outcome.

Service structure was noted to create opportunities for continuity of care with initiatives including:

- transitional workers
- transitional teams
- professional continuing education
- information for professionals
- use of existing continuous services
- inter- and intra-organisation liaison and agreements
- organisational planning
- frameworks and fostering equity and accessibility.

Consideration of these structural components of a service is recommended.

Equally important to service delivery are process components including specific actions which foster continuity at the transition. Service initiatives identified include:

- preparation for transition
- active management of transition
- case management
- accountability for the process
- strong therapeutic relationships
- advocacy
- joint management of care
- flexibility regarding point of transfer
- specific communication systems
- regular audit of service provision.

Consideration of these components within a transition service is recommended.

Many outcome components are inevitably disorder-specific; however, some are generic, such as user satisfaction. Outcome components provide benchmarks against which service quality may be measured and their consideration for this purpose is recommended. Clearly, it will be impossible to move beyond the current position of 'weak evidence' unless a range of robust outcome measures and outcome-based evaluation strategies are developed and widely adopted. The adoption of such methods needs to be instigated through two channels: research, to

ensure that new knowledge and models of transitional care are developed and their worth assessed; and audit, to ensure that standards, once adopted, are maintained. Indeed, such data, if collectively reported to various levels within the health and social care infrastructure, locally and nationally, could provide an important focus for quality in transitional care provision. It is cautioned, however, that outcome measurement should be considered in union with structure and process measurement, given the multifaceted and highly contextualised nature of the types of initiatives involved in addressing continuity.

The perspective of the recipient of care – that is, the user – is central to any consideration of quality of care provision. There are two user groups regarding transition: the young people and parents/families, and their needs require separate consideration. Further, it is important to note that service users are not homogeneous groups and are as heterogeneous as the general population with their only shared characteristic being that they are users of services at the transition. Components of good practice regarding young people include:

- specific service provision

- development of skills of self- management and self-determination

- supported psychosocial development

- involvement of young people

- peer involvement

- support for changed relationships with parents/carers

- provision of choice

- provision of information

- focus upon young person's strengths for future development.

Consideration of these components for service development is recommended.

There was little literature regarding good practice with parents and carers but the centrality of these users cannot be neglected by service providers. The limited initiatives include:

- support for adjustment to changed relationships with young people,

- parental involvement in service planning

- a family-centred approach

- provision of information.

Consideration of these components is also recommended.

In addition to these general recommendations, the following more specific recommendations are offered.

- Continuity in the care transition must be examined in parallel with the young person's physical, social and psychological growth and development.

Components of practice in the transition from child to adult care

- Continuity in this transition is multidimensional and researchers and practitioners should try to account for all these dimensions even when focusing on only one or two.

- Practitioners and researchers need to be specific about the dimensions of continuity they aim to address, and employ the most appropriate methods for responding to or examining those dimensions.

- The components for practice, framework and models of continuity promotion developed through this review need to be further refined and explored through primary research in practice settings.

- Continuity in this transition needs to consider the perspectives of the services, the young person and the family. At present there is a strong emphasis upon services and more work is needed to examine the perspectives of young people and their families and their role in continuity.

- In reporting or evaluating an intervention or practice aimed at addressing continuity through the transition, the following factors should be considered and addressed in an evaluation report:
  – the nature of the user population
  – the dimensions of continuity being addressed
  – a careful description of the structure and process of the intervention, with linkage to the dimensions of continuity
  – if multiple interventions or whole programmes are being implemented, the usefulness of trying to examine both the individual and aggregate impact of the major elements within the programme – or at least providing sufficient description of each element
  – use of outcome measures which are appropriate to the dimensions of continuity being examined and which address the areas expressed in Section 3.4.1.3.iv
  – following the young person through the transition and, where feasible, long-term follow-up.

6 Conclusion

This review has sought to bring together a broad range of practices which aim to enhance the continuity of care for young people with chronic diseases or disabilities in the transition from child to adult care. The promotion of continuity of care during this transition is an important dimension of a high-quality service provision. However, continuity of care at the transition needs to acknowledge the unique needs of young people within the context of their psychosocial development, in addition to the dimensions of continuity identified by Freeman *et al.* (2000). Thus, consideration of developmental continuity presents an additional challenge to service providers with its neglect potentially having major implications for the young person's adoption of new life roles associated with adulthood and full citizenship.

A framework for service development comprising seven discrete phases of a cycle has been proposed to guide service providers. The review revealed four underpinning models of continuity promotion which lie along a continuum of service focus. The four models are proposed as 'ideal types' with particular strengths in meeting the needs of young people with specific support needs, thus providing service providers with potential models upon which to develop services. The testing of these models regarding their ability to achieve the different dimensions of continuity of care is needed. Indeed, the paucity of robust evidence is a major impediment to the development of services founded upon tested interventions and service models. Thus, while the review has identified a large number of potential components of good practice relating to service provision (structure, process and outcome), young people and parents/carers, it is acknowledged that a recommendation for their consideration within service development must be cautious without evidence of their effectiveness. This review, however, provides a basis for the development of research to inform effective service provision.

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Appendices

Appendix 1 Databases and search terms

Databases

Medline, Embase, Cinahl, PsycInfo, Cochrane Library, Best Practice, HMIC, Science & social science citation indexes (WoS), Assia, Social Services Abstracts, Sociological Abstracts, Caredata, International Bibliography of social Sciences (IBSS), Eric, BEI, National Research Register, HEA database, ChildData (National Children's Bureau), Current Research in Britain, NICE, SMAC, SIGLE

Key Face – Continuity (used in Searches A and B)

Indexed terms

Continuity of patient care (before 1990 primary health care)

Patient transfer

Keywords

Use truncation and adjacency operator

Sustain$ adj15 care   sustain$ adj15 service$

Transfer$ adj15 care   transfer$ adj15 service$

Transition$ adj15 care   transition$ adj15 service$

Continu$ adj15 care   continu$ adj15 service$

Patient transition/transfer

Transition$ planning

Transition$ program$

Target population (used in Searches A and B)

Indexed terms

Pediatrics

Adolescence

Adolescent health services

Keywords

Pediatric$

Paediatric$

Adolescen$

Teenage$

Youth$

Young people

Young person$

Young adult$

Child$4 (limit truncation if possible to remove terms such as childbirth)

Tracer conditions (used in Search B)

Learning disability	Congenital heart disease	Muscular dystrophy	Diabetes mellitus	Cystic fibrosis
Indexed terms	*Indexed terms*	*Indexed terms*	*Indexed terms*	*Indexed terms*
Learning disorders/	Explode congenital heart defects/	Exp muscular dystrophies/	Exp diabetes mellitus/	Cystic fibrosis/
Explode mental retardation/				Mucovicidosis
Explode cognition disorders/				
Keywords	*Keywords*	*Keywords*	*Keywords*	*Keywords*
Learning disorder$	Congenital heart disorder$	Muscular dystroph$	Diabet$	Cystic fibrosis
Learning disabilit$	Congenital heart abnormalit$	Distal myopathies	Diabetes mellitus	
Learning disturbance	Congenital heart defect$	Myodistrophica		
Mental retard$	Congenital heart disease$	Myodistrophy		
Mental disab$				
Cogniti$ disorder$				
Cogniti$ disab$				

Appendix 2 Methodological filter

1	randomized controlled trial.pt.
2	Controlled clinical trial.pt.
3	intervention studies/
4	experiment$.tw.
5	(time adj series).tw.
6	(pre test or pretest or (posttest or post test)).tw.
7	random allocation/
8	impact.tw.
9	intervention?.tw.
10	chang$.tw.
11	evaluation studies/
12	evaluat$.tw.
13	effect?.tw.
14	comparative studies/
15	animal/
16	human/
17	15 not 16
18	or/1-14
19	18 not 17

(Example shown above is for use on Medline.)

Appendix 3 Charitable, voluntary and government-funded organisations contacted

Organisation	Information about transition (Yes/No)	Nature of information about transition
Barnardos	Yes	Relevant publications about transition
British Heart Foundation	No	Recommended contacting GUCH and a Cardiac Consultant at the Royal Brompton
Children's Heart Federation	No	However, their fact sheet recommends that health authorities budget for separate facilities for adolescent inpatients with heart conditions
The Children's Society	No	Sent list of other contacts
Connexions	Yes	Document from web site describing transitional support for young adults and other information about the service around the country
Council for Disabled Children	Yes	Publications addressing transition
Cystic Fibrosis Trust	Yes	Various information sheets and leaflets regarding transition
Diabetes UK	No	But mentioned that they have provided funding for NCB to carry out research into transition for young people with diabetes
Down's Heart Group	No	No publications about transition but could relate experiences of transition for children with Down's syndrome
Family Fund Trust	Yes	Publication about options after 16 years of age for young people with disabilities
GUCH (Grown Up Congenital Heart Patient's Association)	Yes	Information sheet about transition and list of further contacts including Down's Heart Group
Joseph Rowntree Foundation	Yes	Publications about transition
King's Fund	No	Recommended other agencies
MENCAP	Yes	Report about transition for young people with disabilities (Ealing)
Muscular Dystrophy Campaign	No	No information available
National Children's Bureau	Yes	Currently carrying out research into transition for young people with diabetes – sent fact sheet and information about this research
National Development Team	Yes	Publication about transition

(continues on next page)

Appendix 3 Charitable, voluntary and government-funded organisations contacted (continued)

Organisation	Information about transition (Yes/No)	Nature of information about transition
NCH Action for Children	No	Suggested we contact SKILL – the national charity for students with learning difficulties and disabilities
NSPCC (Library & Information Service)	Yes	Reference list of relevant publications
SKILL (Charity for students with learning and physical disabilities	No	No response to various phone messages left
Values into Action	Yes	Publication about transition (*Making Our Own Way* – Tony Ryan)

Appendix 4 Survey questionnaire

Florence Nightingale School of
Nursing
and Midwifery

KING'S
College
LONDON
Founded 1829

Multi-method review to identify different practice models which aim to facilitate continuity in the transition from child to adult care

We have been commissioned to identify practice models which facilitate continuity in the transition from child to adult care. We would like you to identify any services or initiatives which help young people transfer from child- to adult-based services. To help you, these are some of the initiatives of which we are already aware: documentation; the provision of specialist transitional posts or teams; relationships between child and adult services; the provision of care facilities and other equipment and identification of care pathways. However, please do not be restricted by these suggestions.

In this questionnaire we have included some disorder groups for which we have a particular interest. Again, please do not be restricted by these examples. Where indicated, could you also please provide details of a person who could tell us more about the services or initiatives mentioned, so that we may follow up any examples which you identify. Any information which you provide will be treated confidentially and services will only be identified in reports following formal written consent; otherwise they will be described anonymously.

We are grateful for your help and appreciate the time which this questionnaire will take for completion. If you have any queries regarding the questionnaire or the project please contact Samantha Lewis by telephone on 020 7848 3108 or by

e-mail at:samantha.lewis@kcl.ac.uk.

Question 1

What is your job title?

....

Please provide your contact details below.

Address:

....

....

....

Telephone:

....

e-mail:

....

Question 2

Please indicate below services for children and young people for which you are responsible.

❑ Commissioning

❑ Planning

❑ Managing

❑ Providing

Please list the services for which you are responsible:

Question 3

(a) Please indicate whether you or the service for which you are responsible provides care to children and young people with the following disorders/difficulties.

❑ Congenital heart disease

❑ Cystic fibrosis

❑ Diabetes mellitus

❑ Learning disability

❑ Muscular dystrophy

❑ Children with physical disability

❑ Children with complex or multiple problems

❑ Other (please give details below)

Components of practice in the transition from child to adult care

(b) Does your work include 'looked after children' (i.e. children for whom responsibility is held by the Local Authority)?

❑ Yes

❑ No

(c) For each of the above groups of children detailed in Questions 3(a) and 3(b) what happens to most of them when they reach adulthood?

	Not applicable	Client discharged	Client referred to adult services without handover	Client referred to adult services with handover	Intermediate and transitional care arrangements are made
Congenital heart disease	❑	❑	❑	❑	❑
Muscular dystrophy	❑	❑	❑	❑	❑
Cystic fibrosis	❑	❑	❑	❑	❑
Children with physical disability	❑	❑	❑	❑	❑
Diabetes mellitus	❑	❑	❑	❑	❑
Children with complex or multiple problems	❑	❑	❑	❑	❑
Learning disability	❑	❑	❑	❑	❑
Other (please give details below)	❑	❑	❑	❑	❑
_____	❑	❑	❑	❑	❑
_____	❑	❑	❑	❑	❑
_____	❑	❑	❑	❑	❑
	❑	❑	❑	❑	❑

(d) Does your organisation employ any of the following to support the child during transition to adult services? (Please tick all categories that apply.)

❑ A transition team (a half-way house to support young people to access adult services)

❑ Joint working with adult service providers

❑ Joint working between adult and children's services providers

❑ Partnership approaches involving the young person in planning their own transfer to adult services

❑ Shared documentation and record keeping system

❑ Use of out-of-clinic support groups to support young people as they move into the less structured life of adulthood

❑ Other (please specify):

Question 4

Has there been any formal/informal evaluation of the initiatives which you have identified above?

❑   Yes

❑   No

If so:

Who did it?

....

When was it done?

....

Is there a report?

❑   Yes

❑   No

Whom should we contact for a copy of the report?

....

....

Question 5

Please provide contact details of key persons for any of the services or strategies which you have identified:

1 ....

....

2 ....

....

3 ....

....

4 ....

....

Please use the space below to provide any extra information.

Thank you for your time and co-operation with this project.

Please return the questionnaire in the envelope provided to:

Samantha Lewis
Primary & Intermediate Care Section
Florence Nightingale School of Nursing & Midwifery
King's College London
James Clerk Maxwell Building
57 Waterloo Road
London, SE1 8WA

Appendix 5 Key informants

Service	Job titles	Total number of staff contacted	Total number of questionnaires returned
Social Services	Service Managers	43	13
	Directors of Social Services/Children's Services/Children & Families		
	Chief Officers		
	Head of Services _ Children & Families		
	Planning/Business Development Managers		
Paediatric nursing teams	Team Leaders	31	18
	Clinical Nurse Specialists		
	Community Paediatric Sisters/ Senior Community Paediatric Nurses		
	Paediatric Community Nurse Managers		
	Paediatric Co-ordinators		
Local education authorities	Head of Pupils Services/Special Educational Needs/Learner Support Services	43	28 (inc. 1 incomplete)
	Education Officers		
	Service Managers		
	Directors of Education		
	Assessment Managers		
	Team Leaders		
Child development teams	Consultant Paediatricians/Community	40	13
	Paediatricians		
	Child Development Team		
	Co-ordinator/Administrator/Special Needs Co-ordinator		
	Team Leaders		
	Primary Care Managers		
	Heads of Service/Programme Managers		
Health authorities	Directors of Services – Children & Young People	23	17 (inc. 1 declined)
	Consultants		
	Commissioning Managers/Heads of Commissioning Service		
	Managers/Project Managers/Programme Managers		
	General Managers		
Learning disabilities	Service Managers/Directors	36	22 (inc. 1 declined)
	General Managers		
	Senior Social Workers		
	Consultants		
	Heads of Service		

Appendix 6 Critical appraisal instruments

6i Item assessment schedule (condensed)

Reference number	Comments	Score
Authors/Year		
Title/Ref.		
Item format		
Type of intervention		
Key components		
Target population (inc. age range)		
Aim(s)		
Location of intervention		
Funding		
Structure (who and how)		
Process (what they do)		
Outcomes		
Costs		
User participation		
Other comments		
Total		

6ii Scoring schedule: quantitative studies or studies addressing outcome (refer to EPOC guidelines)

	Questions	Score				
1	Was the study prospective (stronger) or retrospective (weaker)?	Retro = 1 Prosp = 3				
2	Were the outcome measures appropriate and clearly linked to the intervention?	0	1	2	3	4
3	What method was used for the study? (Grade methods I–IV, see Bandolier for levels.)	0	1	2	3	4
4	Were the methods adequately described and appropriate – following EPOC guidelines?	0	1	2	3	4
5	How strong was the impact of the intervention on the identified outcomes?	0	1	2	3	4
6	How accurate/precise was the measure of impact (p-values and CI)?	0	1	2	3	4

Summary score

Weak	Moderate	Strong
0–9	10–16	17–23

Components of practice in the transition from child to adult care

6iii Scoring schedule: qualitative0 studies (refer to CASP guidelines)

Questions	Score				
1 Was there a clear statement of the aims of the research?	0	1	2	3	4
2 Was the sampling strategy clearly justified and linked to the target population?	0	1	2	3	4
3 Were the data collection methods adequately described?	0	1	2	3	4
4 Was the data analysis clearly linked to the themes/categories identified?	0	1	2	3	4
5 Were the themes and categories linked to the aims of the research and plausible?	0	1	2	3	4
6 How transferable were the study's findings?	0	1	2	3	4
7 What was the strength of the implications of the study for practice?	0	1	2	3	4

Summary score

Weak	Moderate	Strong
0–11	12–20	21–28

6.iv Scoring schedule systematic reviews (answer either 6 or 7, *not* both)

Questions	Score				
1 Was the focus/question of the review clear?	0	1	2	3	4
2 Was the search strategy clearly identified and appropriate?	0	1	2	3	4
3 Was the search for materials/evidence comprehensive?	0	1	2	3	4
4 Were quality control (inclusion/exclusion) criteria used in identifying the materials/evidence?	0	1	2	3	4
5 Was each retrieved item identified and critically appraised following explicit criteria?	0	1	2	3	4
6 If the review incorporated a meta-analysis:					
(a) Was the type of intervention and the target population clearly identified and consistently applied?	0	1	2	3	4
(b) Were the outcome measures appropriate and consistently applied?	0	1	2	3	4
(c) Overall, how strong was the impact of the intervention on the identified outcomes?	0	1	2	3	4
(d) Overall, how accurate/precise was the measure of impact (p-values and CI)?	0	1	2	3	4
7 If the review was theoretically based:					
(a) Was the theoretical review comprehensive?	0	1	2	3	4
(b) Were each of the theoretical positions adequately described?	0	1	2	3	4
(c) Were the theoretical positions adequately critiqued?	0	1	2	3	4
(d) Were the theoretical concepts identified linked to practice?	0	1	2	3	4

Summary score

Weak	Moderate	Strong
0–11	12–24	25–36

Appendix 7 Result of searches

Search A

Number of hits = number of references resulting from search strategy

Papers selected = Papers chosen from number of hits for follow-up

Medline	Embase	Cinahl	WoS	HMIC	Sociological Abstracts	Psychinfo	Social Services Abstracts	BNI	BEI	Caredata
1900 hits	1057 hits	353 hits	67 hits	21 hits	24 hits	110 hits	92 hits	12 hits	94 hits	346 hits

Total number of hits = 4076

Number of papers selected = 172

Number of cases of practice identified = 61

Search B

	Medline	Embase	Cinahl	Eric	Sigle	Caredata	Psychinfo	WoS	Childata
Diabetes mellitus	103 hits 8 papers selected	52 hits 4 papers selected	5 hits 2 papers selected	N/A	N/A	N/A	N/A	N/A	N/A
Congenital heart disease	63 hits 6 papers selected	13 hits 6 papers selected	23 hits 4 papers selected	N/A	N/A	N/A	105 hits 3 papers selected	N/A	N/A
Cystic fibrosis	40 hits 8 papers selected	21 hits 10 papers selected	13 hits 8 papers selected	N/A	N/A	N/A	N/A	67 hits 4 papers selected	N/A
Muscular dystrophy	6 hits Not relevant	1 hit Not relevant	1 hit 1 paper selected	3 hits 1 paper selected	N/A	N/A	N/A	N/A	N/A
Learning disability	107 hits 27 papers selected	134 hits 8 papers selected	36 hits 20 papers selected	200 hits 24 papers selected	6 hits 3 papers selected	29 hits 5 papers selected	118 hits 15 papers selected	N/A	56 hits 3 papers selected

Total number of hits = 1202

Number of papers selected = 170

Number of cases of practice identified = 39

It is estimated that there were about 15 papers of those selected for further scrutiny in Search B that we were unable to obtain, some of which were foreign papers, some of which were on microfiche films.

Search C

Organisations or others recommending publications	Number of papers/reports publications/correspondence describing transition	Number of items describing transition practice
Services participating in questionnaire survey who referred to a report about their transition service or enclosed further information	20	18
Barnardos	1+	0
Council for Disabled Children	3	3
Cystic Fibrosis Trust	Booklet and fact sheets	0
Family Fund Trust	Resource guide for disabled people over 16	0
GUCH	Fact sheet	0
Joseph Rowntree Foundation	1+	0
MENCAP	Report about transition in Ealing	1
National Children's Bureau	Fact sheet	0
National Development Team	Publication about transition	1
NSPCC	5	0
Oxfordshire Joint Health, Social Services & Education Project	1	1
Values into Action	1	0
Additional papers identified by Transition Research Team Members	4	3
Total	**41**	**26**

Appendix 8 Summary table of reviewed items

Key

Item type:

1 = Description

2 = Evaluation

3 = Survey/Interview/User accounts

4 = Review/Report

Strength of evidence:

S = Strong

M = Moderate

W = Weak

Components of practice in the transition from child to adult care

Ref. number	Author(s)	Item type	Strength of evidence	Location	Sample	Design and intervention	Findings and comments
1	Allen-Meares, P., 1988	3	W	Education/Social Services/Vocational Training, USA	Moderately to severely handicapped school-leavers Age 18+ years (n = 38)	Interview-based case study of community-based agency providing vocational services to handicapped youths	Problems identified with the conceptualisation and implementation of an inter-agency agreement for transition. Recommended closer links between the social worker, the school and community-based vocational services.
2	Alper, S., 1990	3	M	Education, USA	Parents of severely disabled school-leavers Age 16–21 years (n = 103)	Questionnaire survey to elicit parents' perceived needs for themselves, parental participation in school programmes, communication with the school and satisfaction with school programme	Parents' indicated a need for more information on work options for their children, adult service agencies and community living options. Almost half the respondents wanted to participate in parent groups and be involved in finding jobs for their children, while only 15% reported actual participation. Most parents reported occasional communication with the school, usually by telephone. 62% of parents reported they were very satisfied with the school programme.
3	Ames, T.R., 1970	1	N/A	Education/Voluntary Sector, USA	Young adults with mental handicap Age 16+ years (No sample)	Description of a transition programme to promote independence	Programme aimed to promote independence and integration into the community, e.g. through employment.
4	Anonymous 1, 2001	1	N/A	Health, UK	Young people with learning disabilities Age not specified (No sample)	Description of transition service	Health summary from school forwarded to GP. Multidisciplinary team meeting at secondary school with student, parents, children's team, adult team, school nurse, careers advisors, teachers, GP, consultant of rehabilitative medicine.

Components of practice in the transition from child to adult care

Ref. number	Author(s)	Item type	Strength of evidence	Location	Sample	Design and intervention	Findings and comments
5	Anonymous 2, 2001	1	N/A	Social Services, UK	Young people with disabilities Age 14–25 years (No sample)	Description of transition service	Transition Specialist Worker providing intensive service to enhance opportunities for young people with disabilities and their families. Provides workshops in the holidays, work experience scheme, and activity/leisure groups.
6	Anonymous 3, 1999	3	W	Health/Education/ Social Services, UK	School-leavers with physical disabilities only (n = 14)	Draft report of study of young people's experiences of transition	Many of the young people found transition particularly distressing. They reported not being involved in decision making and were not given enough time to discuss the plans and their future.
7	Anonymous 4, 2001	1	N/A	Social Services/Health, UK	Young people with moderate–severe learning disabilities Age 14–19 years (No sample)	Describes community-based transition service – the Community Adolescent Transition Service (CATS)	Referrals to CATS team from clients, carers and other professionals. CATS social workers attend educational transition reviews where possible. Planning with service users and carers around future care needs. CATS team is jointly commissioned by Social Services and Health.
8	Anonymous 5, 2000	1	N/A	Social Services, UK	Young people with disabilities preparing to leave school Age 13+ years (No sample)	Describes assessment service by transition team for school leavers with disabilities	Social work transition team carry out assessment of needs for young disabled people. Involves liaison with education and health care professionals to transfer the young person to adult services.
9	Anonymous 6, 2001	1	N/A	Social Services/Health/ Education, UK	Young people with disabilities Age 14+ years (No sample)	Describes transition process	Programme includes: multidisciplinary working, transition planning, review meetings and transition meetings involving young person, carer and multidisciplinary team.

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Ref. number	Author(s)	Item type	Strength of evidence	Location	Sample	Design and intervention	Findings and comments
10	Anonymous 7, 2000	1	N/A	Social Services, UK	Young people with disabilities Age 14+ years (No sample)	Describes transition service provided by Haringey Social Services	Recommends 14 key issues for future transition planning: assessment, coordination, information, employment, learning opportunities, user participation, user choice, continuity, communication, housing, transport, friendship, postponement and clarity.
11	Anonymous 8, 2000	3	W	Health, UK	Young people with learning disabilities Age not specified (n = 137 families)	Audit of Parent Adviser Service of the community learning disability team	The Parent Adviser Service was set up to work with the family, the young person and the multidisciplinary team to promote independence. Audit uncovered an under-resourced service, with some Parent Advisers being responsible for up to 37 families.
12	Anonymous 9, 2001	4	Summary of report only	Social Services, UK	Young people leaving care Age not specified (Sample size not specified)	Best Value Review Aftercare Action Plan accompanying Report	The action plan aimed to help young people into employment or further education. 75% of care leavers felt that they had received appropriate support. The review found 5 distinct, yet overlapping areas for further attention: housing, education, employment, consultation, financial support.
13	Anonymous 10, 2000	1	N/A	Health, UK	Young people with congenital heart disease Age 16+ years (No sample)	Description of transition clinic	Multidisciplinary team of professionals meet regularly to discuss cases across all age groups to ensure continuity of care.
14	Anonymous 11, 2001	1	N/A	Voluntary sector, UK	Looked-after children and young people with or without disability Age 0–21 years (No sample)	Describes RESPECT – Children's Rights & Advocacy Service, for looked-after children and young people with and without disabilities	The service advocates for young people in terms of their needs, assisting with the transition process. The advocate works with the young person so that they have full involvement in their own transition.

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Ref. number	Author(s)	Item type	Strength of evidence	Location	Sample	Design and intervention	Findings and comments
15	Anonymous 12, 1999	1	N/A	Social Services, UK	Young people with learning disabilities Age 0–19 years (No sample)	Describes transitional planning policy for school leavers with a learning disability	Transitional planning comprises: • LEA Annual review core assessment • adult services information and consultation link • adult services and community nurse allocation • adult services care and financial management • visits to adult setting with Social Worker or Community Nurse.
16	Anonymous 13, 2000	1	N/A	Education, UK	Young people with special educational needs Age 14+ years (No sample)	Describes transition plan for young people with special educational needs	Transition process consists of an annual review and the drawing up of a transition plan involving the student, the parents, the careers officer, school SENCO and other relevant school staff, plus staff from any support agencies involved with the education plan.
17	Anonymous 14, 2001	1	N/A	Social Services/Health, UK	Young people with learning disabilities Age 14+ years (No sample)	Description of protocol for young people in transition	Young people with learning disabilities are referred to adult transition workers at the age of 14 who manage the transition process.

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Ref. number	Author(s)	Item type	Strength of evidence	Location	Sample	Design and intervention	Findings and comments
18	Anonymous 15, 2000	4	W	Health/Social Services, UK	Young people with global learning disabilities Age 14–18+ years (No sample)	Report on Islington Transition Project	Project involves: inter-agency planning meetings with disabled children's team, special needs education staff, children and families placement officer, health professionals, Camden adult learning disability team, Mencap representative. Joint protocols, guide for transition and appointment of a transition worker have resulted from this project.
19	Anonymous 16, 1997	3	W	Social Services/Health, UK	Young people with a learning disability with a statement of special educational need Age 14–19 years (n = 10 young people; n = 7 family members; n = 11 keyworkers)	Consumer satisfaction survey of the Community Adolescent Transition Service (CATS)	No clients felt that they required any additional help further to that they had received. 100% felt that they were listened to. 80% reported that they had been helped a lot to care for themselves. 88% of family/caregivers felt that help from the CATS team had benefited the client a lot. All comments by keyworkers about the service and professionals were positive.
20	Aune, E., 1991	1	N/A	Education, USA	Post-secondary bound students with learning disabilities Age not specified (n = 55)	Description of model preparing students with learning disabilities for transition to post-secondary education	The model aimed to encourage better study habits, provide more knowledge about options available and help students to acknowledge their learning difficulties.
21	Beecher, W., 1998	1	N/A	Voluntary sector, UK	Young people with disabilities Age not specified (No sample)	Compendium of resources to help families and young people address issues they face during transition to adulthood	Describes useful organisations, educational opportunities, training and employment, money matters, independent living, housing, equipment and social networks.

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Ref. number	Author(s)	Item type	Strength of evidence	Location	Sample	Design and intervention	Findings and comments
22	Bergman, P.E. *et al.*, 1995	3	M	Health, USA	Young people involved in substance abuse Age 12–19 years (n = 1483)	Retrospective national survey to describe population of young people involved in substance abuse treatment programmes, and outcomes of treatment	40% of young people reported total abstinence for one year following treatment programme. 70% of young people reported substance use was no more than once per month.
23	Betz, C.L., 1998	4	M	Health/ Education, USA	Young people with chronic illness Age 14+ years (No sample)	Description of roles of school nurses and clinical nurses in transition programmes	Use of the nursing process to facilitate individualised care planning. Emphasises importance of joint planning with young person and the family to identify services congruent with family values and culture.
24	Betz, C.L., 2000	1	N/A	Health, USA	Young people with special health care needs Age not specified (No sample)	Description of guidelines for teaching health care skills	Transition guidelines containing a broad range of health care self-care competencies. Nurses work closely with young people and their families to promote self-sufficiency and independence.
25	Blalock, G., 1996	4	W	Education, USA	Young people with learning or other disabilities Age not specified (No sample)	Review of community transition teams in the USA for young people with learning or other disabilities	Conclusion: community transition teams are a viable mechanism for improving local services for young people with disabilities.
26	Blum, R.W., 1995	4	W	Health, USA	Young people with chronic illness or disability Age not specified (No sample)	Overview of health care needs and service provision to young people with disability or chronic illness	Includes discussion of specific needs of young people and age-specific services. The importance of considering the social and environment and the role of the family in the young person's life is underlined.

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Ref. number	Author(s)	Item type	Strength of evidence	Location	Sample	Design and intervention	Findings and comments
27	Bowes, G. *et al.*, 1995	4	W	Health/Education, international	Disabled and chronically ill young people Age not specified (No sample)	Overview of approaches to transition in Australia, Holland, Spain and Switzerland	Illustrates how organisational structure and funding impacts upon access to, availability of, and transition services.
28	Brollier, C. *et al.*, 1994	1	N/A	Education/Vocational Training, USA	Young people with disabilities Age 12–22 years (No sample)	Description of school-based occupational therapy transition programme	Programme includes: functional life skills assessment and training in real-life settings, environmental modification and psychosocial skills training to promote independent living and achieve gainful employment.
29	Brunswick, A.F., 1984	3	M	Health, USA	'Urban Black Youth' – health care needs Age 12–23 years (n = 536)	Longitudinal, prospective interview survey to examine the relationship between medical care utilisation and health	Findings suggest that a continuous source of care for young men has positive health effects. This relationship was not evident for young women, who reported more health problems at an earlier age.
30	Brunswick, A.F. and Merzel, C.R., 1988	3	M	Health, USA	'Urban Black Youth' – health care needs Age 12–31 years (n = 426	Longitudinal, prospective interview survey to examine coherence and change in perceived health status during and after adolescence	Findings revealed a significant increase in perceived health problems during late adolescence (age 18–23) compared with early–mid adolescence (age 12–17). Health status was then seen to stabilise during the post-adolescence period (age 24–31). This finding was interpreted as a reflection of the increase in stress experienced by this group of young people during late adolescence.
31	Bucher, L.M., 1995	2	Abstract only	Health, USA	Young people with disabilities Age not specified (No sample)	Evaluation of transition program for young people in special education	Study looked at dimensions of transition such as personal and social networks, leisure and recreational pursuits and independent living status. Finding: success in one area of transition was independent of success in other areas.

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Ref. number	Author(s)	Item type	Strength of evidence	Location	Sample	Design and intervention	Findings and comments
32	The California Healthy and Ready to Work Team (Website, undated)	1	N/A	Health/Education, USA	Young people with special health care needs and/or disabilities Age not specified (No sample)	Describes background to project, its objectives, a framework for teaching self-care skills and transition health care assessment	Transitional programme offers expertise and linkages with partner agencies to resolve transitional issues such as transfer to adult health care services, employment and independent living. Key components of project: inter-agency collaboration; advocacy, family centred; transition services co-ordinator.
33	Cappelli, N.E. *et al.*, 1989	3	M	Health, Canada	Young people with cystic fibrosis Age not specified (No sample)	Questionnaire and interview survey to elicit views of caregivers and young people regarding transition	Aim: to support successful and appropriate transfer to adult care by assessing readiness of young people prior to transfer.
34	Carson, C., 1998	1	N/A	Health, UK	Young people with diabetes Age 14–18 years (No sample)	Description of specialist nurse transition service	The service attempted to maintain young people with diabetes within the health care system and to reintroduce defaulters.
35	Conway, S.P., 1998	4	W	Health, UK	Young people with cystic fibrosis Age 12+ years (No sample)	Review of transition models for cystic fibrosis patients	Discusses various transition models of care in the UK and USA where staff work either between paediatric and adult units or in dedicated adolescent units. The need to help parents to let go is also emphasised.
36	Council for Disabled Children & the National Development Team, 1999	3	W	Social Services, UK	Young people with disabilities/special educational needs Age not specified (No sample)	Survey of parents and users	Recommends professional development in transitional issues, inter-agency and strategic planning; co-ordination role and parental involvement.

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Ref. number	Author(s)	Item type	Strength of evidence	Location	Sample	Design and intervention	Findings and comments
37	Court, J.M., 1993	3	W	Health, Australia	Young people with Type 1 diabetes Age 16–18 years (n = 105)	Survey of young people's views of transition service	Late teenage years were identified as the best time for transfer to adult services. Young people preferred continuity of care provided through meeting the adult physician in the paediatric environment and getting to know them through regular visits prior to transfer. Privacy, optimum waiting conditions, informality and health education were also deemed important.
38	Crosnier, H. and Tubiana-Rufi, N., 1998	3	W	Health, France	Young people with Type 1 diabetes Age 15–18+ years (n = 50 paediatricians; n = 51 diabetologists)	Evaluation of transition to adult service	Difficulties maintaining communication between paediatricians and diabetologists were identified. Physicians were keen to develop multidisciplinary meetings to co-ordinate the transition to adult care.
39	Dalke, C. and Schmitt, S., 1987	1	N/A	Education, USA	Young adults with learning disabilities Age 17-20 years (No sample)	Describes Project ASSIST, a high school to college transition programme	A 5-week summer transition programme to prepare students with learning disabilities for college life.
40	Dattillo, J. and St. Peter, S., 1991	1	N/A	Education, USA	Young adults with mental retardation Age not specified. (No sample)	Describes a leisure education model	Aim: to instil self-determination, leisure appreciation, self-awareness, decision making, social interaction and knowledge and utilisation of leisure resources into the lives of young people with learning difficulties.
41	DeFur, S H. and Taymans, J.M., 1995	3	M	Education/ Vocational Training, USA	Transition specialist practitioners (n = 149)	Questionnaire survey of expert opinion to identify and validate competencies for transition specialist practitioners	Findings provide a validated knowledge base for transition specialist practitioners. These include communication skills, collaborative working and consultation.

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Ref. number	Author(s)	Item type	Strength of evidence	Location	Sample	Design and intervention	Findings and comments
42	De Rosa, C.J. *et al.*, 1999	3	S	Health/Social Services/Education/ Vocational Training/Voluntary Sector Services, USA	Homeless and Runaway Youth. Age 13-23 years. (n=298)	Interview survey with representative sample to describe service utilization patterns, homelessness history, physical and mental health of street youth.	Youth shelters and drop-in centres were the most used services. Young people reported a high level of satisfaction with these services. Concerns re confidentiality prevented many youth using others centres. Youth reported a need for more job preparation and life skills training.
43	DeSousa, M., 1998	3	W	Health, UK	Young people with chronic renal disease Age not specified (Sample size not specified)	Components of transition programme elicited during focus group discussions with young people attending outpatient clinic	Young people wanted: preparation period of at least one year; a map of the adult-based clinic; list of names of new health care team; an abridged copy of the medical discharge summary; advice and teaching re ordering drugs and registering with a GP; at least one visit to the adult care clinic prior to transfer.
44	DeStefano, L. and Stake, R.E., 1990	4	N/A	Health/Social Services/Education/ Vocational Training, USA	Young people with disabilities. Age not specified (No sample)	Review of methodologies used to evaluate transition programmes	Evaluation designs rely on research methods aimed at theory development. These are often insufficient since the purposes of evaluation include recognising merit, gaining understanding of processes and improving programmes.
45	Dunning, T., 1993	3	W	Health, Australia	Young adults with Type 1 diabetes Age 18–30 years (n = 48 young people; n = 6 clinic staff)	Evaluation of after-hours clinic	Patients and clinic staff concurred on their ratings of 10 of 11 criteria on a Likert scale to assess their satisfaction with the clinic. However, some of the clinic staff were not aware of the patient's option to change appointments. Privacy was an important issue for both groups.

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Ref. number	Author(s)	Item type	Strength of evidence	Location	Sample	Design and intervention	Findings and comments
46	Eiser, C. *et al.*, 1993	3	W	Health, UK	Young people with Type I diabetes. Age under 25 years (n = 69)	Evaluation of patient perceptions of transition to under-25s diabetes clinic	Programme includes diabetes specialist nurse liaising between paediatric and under-25s clinic. Evaluation found that patients did not recall any specific difficulties with the transition, although they noted differences in the aims and attitudes of the staff in the two clinics.
47	Ensign, J. and Gittelsohn ,1998	3	S	Health/Social Services, USA	Homeless young people Age 12–17 years	Multi-method qualitative study to elicit young people's health status and access to health care	The most commonly reported health problems included sexually transmitted diseases, HIV/AIDS, pregnancy, depression, drug use and injuries. Health care interventions need to acknowledge the reality of violence as a daily threat to these young people.
48	Fiorentino, L. *et al.*, 1998	3	W	Education/Health, UK	Young people with a physical disability who had left school Age 16–25 years (n = 87)	Interview-based evaluation of transition process for physically disabled people in three districts of Sheffield	District 1: combined school-leavers assessment team with health, education and social services involvement. District 2: specialist transition nurse. District 3: social worker/careers officer organising transition; multidisciplinary planning meeting.
49	Fiorentino, L. *et al.*, 1998	3	S	Education/Health/Social Services, UK	Young people with a physical disability Age 16–24 years (n = 50)	Survey of young people's experiences of transition between paediatric and adult-based services	Following transfer to adult care, disabled young people experienced a significant reduction in medical and paramedical services. Continuity of service provision was better for young people who had learning difficulties + physical disabilities and who were attending a specialist school.

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Ref. number	Author(s)	Item type	Strength of evidence	Location	Sample	Design and intervention	Findings and comments
50	Fish, T. *et al.*, 1997	1	N/A	Education, USA	Young adults with developmental disabilities/mental retardation Average age 25 years (No sample)	Describes a supported employment training programme	Goal of transition service: supporting young people into meaningful employment.
51	Fothergill, K. and Ballard, E., 1998	3	W	Health/Education/ Social Services, USA	Young people in secondary education Age not specified (n = 21)	Descriptive study of the possibilities and limitations of School-Linked Health Centres; Postal questionnaires + follow-up interviews	The School-Linked Health Centres have an important role to play in providing reproductive health care to a population that is often difficult to reach.
52	Furney, K.S. *et al.*, 1997	3	S	Education/Vocational Training, USA	Young people with disabilities Age not specified (n = 74)	Policy study of transition policies and services in three 'exemplary' states; document analysis and interviews	Themes were identified which contributed to the successful initiation and continuation of transition services including the need for collaborative structures, the strengthening of existing services and empowerment of local communities to make change.
53	Gallivan-Fenlon, A., 1994	3	M	Education, USA	High-school students in last year of public education programme with moderate or severe disabilities Age not specified (n = 11)	Triangulation study of transition programme (interviews, participant observation and document examination)	Found that young people with disabilities and their parents did not fully participate in the transition process and would have liked more information about available options.

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Ref. number	Author(s)	Item type	Strength of evidence	Location	Sample	Design and intervention	Findings and comments
54	Gledhill, S., 1997	1	N/A	Health, Australia	Young adults with cystic fibrosis Age not specified (No sample)	Description of transition process	A 5-phase programme to optimise health, promote autonomy, facilitate activities of daily living, provide psychosocial support and health education. Young people would meet the adult staff in the paediatric environment, followed by a tour and introduction to the adult facilities prior to their first appointment.
55	Godley, S.H. *et al.*, 1994	2	M	Health/Social Services, USA	Young people involved in substance abuse Age under 15–18 years	Describes a case-management model, programme monitoring system and presents evaluation data	90% of young people in programme had contact with case manager every 2–4 weeks as planned. 70% were making progress towards educational/vocational goals. Only 14% had contact with law enforcement. 78% remained abstinent or had 'minor relapses'. Percentage linked with recommended support services 77% (before programme: 40%).
56	Greene, E. and Lucerelli, P., 1999	1	N/A	Health, USA	Young people in prison Age not specified (No sample)	Describes a nurse-led health education programme	Programme developed in collaboration with detained young people. Sessions included stress and anger management, nutrition, sexually transmitted diseases and parenting.
57	Gullotta, T. & Noyes L., 1995	1	N/A	Health/Education/ Social Services, USA	Young people in secondary education Age 10–19 years (No sample)	Describes services provided by School-Linked and School-Based Health Centres	Services include: medical health care (doctors and nurses), mental health care, dental care, health education, social work services.

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Ref. number	Author(s)	Item type	Strength of evidence	Location	Sample	Design and intervention	Findings and comments
58	Hartman, A. *et al.*, 2000	3	W	Health/Education/ Social Services, USA	Young people with special health care needs Age 14–25 years (n = 3)	Case study to examine service and support needs through life history of parents of young people in transition	The lives of young people and their families are influenced by timing and nature of diagnosis, quality of communication with service providers and the degree to which school is able to respond to young person's needs.
59	Hill, J., 1998	1	N/A	Health, UK	Young adults with diabetes Age 18–30 years (n = 120)	Describes a drop-in centre for young people with diabetes	120 people with diabetes were informed about a new monthly diabetes drop-in centre. The average attendance was 4–6 young people/month.
60	Huba, G.J. *et al.*, 1998	1	N/A	Health/Education/ Social Services, USA	Young adults with HIV/AIDS Age not specified (No sample)	Describes a model for service provision based on experiences from 10 pilot projects	5 key elements of service provision identified: peer-youth information dissemination; peer-youth advisory groups; peer-youth outreach and support; tightly-linked medical social support networks, active case management and advocacy.
61	Hyde, K.L. *et al.*, 1996	2	W	Social Services/Private Agency/ Health/ Education/ Voluntary Sector, USA	Young people with severely maladjusted behaviour Age not specified (n = 106)	Describes an intensive case-managed 'wraparound' service and its evaluation (Community Adjustment Rating, community involvement and client satisfaction)	More young people cared for within wraparound service were rated 'good' for community adjustment and were more involved in community. Youth and parent satisfaction with service was high. Non-wraparound groups not meant as true comparison groups, plus low response rates (36–56%), thus undermining the reliability of these findings.
62	Hymel, M.S. and Greenberg, B.L., 1998	2	W	Health/Social Services/Education, USA	Young people with/at risk of HIV/AIDS Age 13–25 years (n = 14)	Describes an intensive, case-managed service and a longitudinal, interview-based study to assess the effectiveness of the service	Young people who remained in the programme reported positive changes on 12 of the 19 life-style and well-being related items. Client-centred relationships were found to be important as were peer staff in providing support.

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Ref. number	Author(s)	Item type	Strength of evidence	Location	Sample	Design and intervention	Findings and comments
63	Jackson, J. *et al.*, 1989	1	N/A	Health/Education, USA	Adolescents in non-mainstream school with developmental disabilities Age not specified (n = 20)	Description of a transition programme	The programme serves 20 of a total of 110 students with developmental disabilities. The programme includes assessment, education, work experience and supported employment, and encourages parental support.
64	Jackson, J., 1990	1	N/A	Education/Vocational Training, USA	Young people with disabilities Age not specified (No sample)	Describes an occupational therapy-based high school transition programme	Programme includes extensive assessment to develop an individualised programme to promote independent living skills using a goal-setting approach. Advancement by incremental steps and risk-taking is encouraged.
65	Jarvis, L.A. *et al.*, 2000	1	N/A	Health, Australia	Young people in prison Age not specified (No sample)	Describes a nursing process-based discharge plan	Transition planning conducted by nurses working with young person, community liaison officer and other agencies if required to ensure young person's health is not compromised following discharge.
66	Johnson, S. and Wehman, P., 2001	4	M	Education/Vocational Training, USA	Young people with disabilities Age not specified (No sample)	Discussion of what and how to teach transition-age students to prepare them for adulthood	Underlines the importance of teaching skills in appropriate community setting. Emphasis on functional skills and activities. Teaching must be focused and employ a wide range of teaching methods.
67	Kaminer, Y., 1999	4	S	Health, USA	Young people involved in substance abuse Age not specified (n = 47 studies reviewed)	Review of methods used to treat substance abuse	Family-based approaches to treatment recommended. Cognitive behavioural therapy and group therapies also shown to work well.

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Ref. number	Author(s)	Item type	Strength of evidence	Location	Sample	Design and intervention	Findings and comments
68	Kinney, T.R. and Ware, R.E., 1996	1	N/A	Health, USA	Young people with sickle cell anaemia Age 13–21 years (No sample)	Describes transition process for outpatient care	Period of preparation for transfer, approx. one year. Health care contract agreed upon by physician and young person – agreed care plan and timing of transfer.
69	Kintner, E., 1997	3	W	Health, USA	Young people with asthma/reactive airway disease Age not specified (n = 6)	Phenomenological study to derive an understanding of acceptance among young people with asthma	It was hoped that an understanding of acceptance of asthma could be used to facilitate acceptance among those young people who were finding it hard to come to terms with their illness and thus promote a healthier lifestyle among this group.
70	Klein, J.D. *et al.*, 2000	3	M	Health/Social Services, USA	Homeless and runaway young people Age 12–21 years (n = 1240)	A nationally representative sample was surveyed to describe their access to, and use of, health services	Half of the street youth and 36% of sheltered youth had no regular source of health care. 25% street youth and 18% sheltered youth reported serious health problems within the preceding year. Recommendation: integration of health care services with other agencies serving street and sheltered youth.
71	Koch, L.C., 2000	1	N/A	Vocational training, USA	Disabled young people leaving school Age not specified (No sample)	Describes career planning interventions designed to improve vocational awareness and ability to manage career development	Interventions include: informational interviews, job shadowing, situational assessment, trial work experiences, voluntary work, development of career portfolios and career planners, ongoing support to aid career maintenance.
72	Kurtz, P.D. *et al.*, 1991	2	M	Social Services/Health/Education, USA	Runaway youth Average age 15.8 years (n = 3519)	Audit of service utilisation and identification of problems through retrospective analysis of client records	Only 33% of runaway youth were regularly attending school; approx. 50% suffered from depression and low self-esteem. Many had left home following a family crisis and reported ongoing family conflict. Lack of parental concern was also common.

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Ref. number	Author(s)	Item type	Strength of evidence	Location	Sample	Design and intervention	Findings and comments
73	Luce, S.C. *et al.*, 1992	1	N/A	Education/Vocational training, USA	Young people with autism and other behaviour disorders Age 8–22 years (No sample)	Describes a continuum of transition services including an intensive vocational training programme	Programme includes special needs assessment to plan goals for education and behaviour change. Ongoing evaluation of effectiveness important aspect of programme.
74	Maclean, W.E. *et al.*, 1995	4	W	Health, USA	Young people who have survived childhood cancer Age not specified (No sample)	Discussion of reasons for transfer to adult-based care and identification of barriers to transition	Four barriers to transition: lack of understanding of the need to acknowledge formally the transitions experienced by the young person; lack of resources; need for health care provider education; unevenness of care.
75	McBroom, L.W. and Tedder, N.E., 1993	2	W	Education/Vocational training, USA	Visually impaired young people Age 19–27 years (n = 12)	Qualitative, interview-based study to compare educationally based with rehabilitative services	Two types of services very similar. Both co-operate with other agencies. Young people and their parents play an important role in service planning. System found to be overly lenient and protective towards young people, as were families, causing a narrow focus in vocations and lack of skills in risk taking and coping with failure.
76	McDonagh, J.E. *et al.*, 2000	3	M	Health, UK	Young people with rheumatoid disease Age 16–25 years (n = 51 units)	Postal questionnaire survey of current service provision (51 of 61 units)	Findings focus on 9 specialist adolescent clinics. Services include: outpatient surveillance, provision of age-specific information regarding disease, general health and lifestyle, disability allowance information, patient education, access to rehabilitation services and hydrotherapy for young people.

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Ref. number	Author(s)	Item type	Strength of evidence	Location	Sample	Design and intervention	Findings and comments
77	Mellin, L.M. *et al.*, 1987	2	S	Health, USA	Young people with obesity problems Age not specified (n = 66)	Randomised experimental study to evaluate the effectiveness of an obesity intervention programme; programme included: voluntary weigh-in, leader-facilitated discussion and exercise	Highly significant improvements were found for young people in the intervention group on five outcome measures: relative weight, weight management knowledge, weight-related behaviour and attitude.
78	Miller, S., 1995	3	W	Health, UK	Young people with chronic illness Age 12–19 years (n = 7)	Qualitative interview study to discover what young people want regarding transition from paediatric to adult care	Key themes included: involvement in decision making; need for information and need for flexible arrangement of clinics to reduce time missed from school.
79	Miller, S., 1996	3	W	Health, UK	Young people with chronic illness Age 12f19 years (n = 7)	Interview study to discover what young people want regarding transition form paediatric to adult care (further analysis of data obtained in earlier study)	Components of care included: gradual transition with overlap of paediatric and adult services, adolescent clinic, good communication between doctors. The role of the nurse in providing health education and promoting independence among this age group is highlighted.
80	Nasr, S.Z. *et al.*, 1992	3	W	Health, USA	Young people with cystic fibrosis Age 17+ years (n = 40)	Evaluation of transition programme	In this programme a pulmonary fellow saw the patients in the paediatric setting under the supervision of the paediatric pulmonologist. The fellow would continue to see the patients once they had been transferred to adult services under the supervision of an internal medicine pulmonologist and after a year their care would be taken over by the internal medicine pulmonologist. The evaluation found positive comments about the transition process and the value of the adult clinic.

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Ref. number	Author(s)	Item type	Strength of evidence	Location	Sample	Design and intervention	Findings and comments
81	Neubert, D.A. and Taymans, J.M., 1989	1	N/A	Education, USA	Young adults with mild learning disabilities Age not specified (n = 66)	Describes a post-secondary time-limited transition model	All 66 participants obtained employment for an average of 10 months. 50% of them worked part-time. A job coach was added to to the team help the young people to maintain employment, obtain further jobs or plan for career advancement.
82	Nochajski, S.M. *et al.*, 1999	1	N/A	Education/Vocational services, USA	Young people with disabilities School age (n = 27)	Describes a service providing assistive technology for computers	Project includes: provision of ACT devices through library; ACT education; work with school personnel. Lending library used by 74% of participants.
83	Oeffinger, K.C. *et al.*, 2000	3	W	Health, USA	Young people who have survived childhood cancer Age 18–34 years (n = 96)	Retrospective clinical study scoring late effects of cancer treatment	24% of patients had asymptomatic Grade 2–4 late effects, needing treatment or close follow-up, detected for the first time at adolescent clinic.
84	Orr, D.P. *et al.*, 1996	2	M	Health, USA	Young adults with Type 1 diabetes Age 17–25 years (n = 82)	Prospective cohort study to evaluate affect on glycaemic control (HbA1 levels) of transferring to adult diabetes programme	No significant changes in glycaemic control were observed in these young adults following transition to adolescent/adult diabetes clinic. This can be viewed as a beneficial outcome as other studies report deterioration in glycaemic control at transfer.
85	O'Sullivan, T., 1999	3	W	Health, UK	Young people with disabilities Age not specified (n = 48)	Interviews with young people with disabilities and their carers in one borough regarding their experience of transition	Recommendations include: need for greater inter-agency planning, long-term planning, more information for young people and carers, the need for advocacy for young people, particularly where language problems exist, and need to address many communities.

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86	Pacaud, D. *et al.*, 1996	3	M	Health, Canada	Young adults with Type 1 diabetes Age 18+ years (n = 135)	Survey of the transfer to adult care from a paediatric diabetic clinic	65% of the respondents felt that they should have been transferred to adult services later. 50% reported some sort of difficulty with transition.
87	Parker, G. and Hirst, M., 1987	3	M	Health, UK	Young adults with disabilities Age 16–22 years (n = 291)	Interviews to assess opinions regarding transition to adult care	Found a failure to ensure continuity of care and practical support during the young people's transition to adult services. A multidisciplinary follow-up and support service was recommended.
88	Partridge, A. and Roiser, M., 1999	2	W	Health/Education/ Social Services, UK	Children and young people with disabilities Age 14+ (No sample)	Description and internal evaluation of an integrated assessment project to support young people with disabilities in future planning	A multi-agency initiative with multidisciplinary assessment.
89	Patterson, D.L. and Lanier, C., 1999	3	M	Health, USA	Young people with special health needs Age 18–35 years (n = 7)	Focus group study to discern young people's transition experiences (grounded theory)	Three strategies for successful transition identified: need to begin transition at very young age; need to prepare family; support during and after transition process (mentor).
90	Pavis, S. *et al.*, 1998	3	M	Health, UK	Young people transitioning from school Age 15–16 years (n = 106)	Interview-based, descriptive study to examine health-related behaviours	Smoking and drinking behaviours were strongly associated with behaviours of friends, the use of leisure time and amount of disposable income.

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Ref. number	Author(s)	Item type	Strength of evidence	Location	Sample	Design and intervention	Findings and comments
90	Pavis, S. *et al.*, 1998	3	M	Health, UK	Young people transitioning from school Age 15–16 years (n = 106)	Interview-based, descriptive study to examine health-related behaviours	Smoking and drinking behaviours were strongly associated with behaviours of friends, the use of leisure time and amount of disposable income.
91	Pearson, M. *et al.*, 1998	3		Health, UK	Young people with learning disabilities Age not specified (n = 260)	Nationwide review using a team of professionals, experts, carers and young people with disabilities	Recommend sequential services ('cradle to grave') and expanding the role of the GP. Transitional planning should be detailed in purchasing contracts. A register of young people with disabilities. Multi-agency collaboration. Accountability arrangements. Review process.
92	Posthill, S.M and Roffman, A.J., 1991	2	W	Education, USA	Young adults with learning disabilities Age 21–31 years (n = 45)	Questionnaire and interview study with young adults to assess their independence and employment success	These young people were found to have benefited from the practical, academic, vocational and independent living training of the programme and were able to make a meaningful contribution to society.
93	Randolph, C. and Fraser, B., 1999	4	M	Health, USA	Young people with asthma Age 11–20 years (No sample)	Review of current knowledge, including adolescent development, epidemiology, diagnosis and treatment	Recommends: multidisciplinary approach; detailed history taking; individualised care planning in partnership with young person; environmental management advice and drug therapy.
94	Rettig, P. and Athreya, B.H., 1991	1	N/A	Health, USA	Young people with rheumatic disease Age 16–19 years (No sample)	Describes a joint medical outpatient clinic	Programme includes joint consultations (paediatrician + adult physician) over 1–2 years; ongoing input from specialist nurse and/or social worker throughout transition period into adult care.
95	Rojewski, J.W., 1989	1	N/A	Education, USA	Young adults with severe learning disabilities Age16-21 years (n = 45)	Description of transition project for high-school students	Project comprises 4 phases: evaluation and assessment; secondary and post-secondary services; job attainment; job retention.

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Ref. number	Author(s)	Item type	Strength of evidence	Location	Sample	Design and intervention	Findings and comments
96	Rosen, D., 1995	4	W	Health, USA	Young people with chronic illness Age not specified (No sample)	Discussion of need for transition to adult-based care and how this might be achieved	Adult care provision increases responsibility and autonomy of young person. Preparation for, and timing of, transition important.
97	Rosenberg, H.C. and Webb, G., 1996	3	W	Health, Canada	Young people with congenital heart disease Age 16 + years (n = 12 cardiology centres)	Survey of paediatric and adult cardiologists regarding transition in cardiology centres	Acknowledged that there was no established process in Canada for referring young adult patients with congenital heart disease to adult services.
98	Russell, P., 1993	3	W	Voluntary sector, UK (King's Fund)	Young people with disabilities Age not specified (n = 60 Social Service departments; n = 40 Education departments)	National survey of key stakeholders relating to issue of transition to national and local levels of care for young people with disabilities	Considers staff development, transitional planning, information and guideline development. Emphasises the involvement of the young person and the parents in transition planning.
99	Russell, P., 1996	3	W	Voluntary sector, UK	Young people with disabilities Age not specified (No sample)	Review of provision for young people with learning disabilities	Recommended: developing a transition plan, changing roles and responsibilities and consulting with the young person.
100	Ryan, T., 1997	3	W	Education, UK	Young people with learning difficulties Age not specified (n = 36)	Survey of opinion regarding transition	Recommended: full involvement of young people in their transition planning, develop schemes to engage these young people in supported employment, and develop housing, health and other local services to include this population.

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Ref. number	Author(s)	Item type	Strength of evidence	Location	Sample	Design and intervention	Findings and comments
101	Ryan, T., 1998	3	W	Education, UK	Young people with learning difficulties Age not specified (No sample)	Summary of Values into Action Report ('Making Our Own Way')	Recommends person-centred planning in the transition planning for young people with learning difficulties and complex needs.
102	Sanci, L.A. et al, 2000	2	S	Health, Australia	Young people with general health care needs Age not specified (n = 108 GPs)	Randomised control trial to evaluate the effectiveness of an educational intervention in adolescent health	Training programme: 6 weekly training sessions plus follow-up session after 6 weeks. Intervention group had significantly improved communication skills, self-perceived competency, and knowledge.
103	Sands, D.J., 1995	1	N/A	Education, USA	Students with mild/ moderate mental retardation Age not specified (No sample)	Description of Live-In Training Experience (LITE)	A community-based living and work experience programme carried out for 8 weeks in the summer prior to leaving school. Students and their family found it to be a beneficial programme.
104	Santelli, J. *et al.*, 1996	4	M	Health/Education/ Social Services, USA	Young people with general health care needs Age: in secondary education (No sample)	Review of service provided by school health centres	Defining attributes identified: first contact, continuous, comprehensive, co-ordinated, community orientated, family-centred and culturally competent care
105	Sawyer, S.M. *et al.*, 1998	2	M	Health, Australia	Young people with spina bifida Age 18+ years (n = 10)	Interview-based qualitative study to establish young people's expectations and concerns on leaving paediatric care, and satisfaction with adult-based service	Concerns included: leaving trusted health professionals and meeting new specialists; worries about transfer of medical records. Dissatisfaction with adult service included: delay in receiving first adult appointment; less-frequent contact; uncertainty of future medical care.

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Ref. number	Author(s)	Item type	Strength of evidence	Location	Sample	Design and intervention	Findings and comments
106	Schidlow, D.V. and Fiel, S.B., 1990	1	N/A	Health, USA	Young adults with cystic fibrosis Age 16–21 years (No sample)	Description of transition clinic	Prior to transfer, patients would be seen by both paediatric and adult caregivers in the paediatric environment, would then see just the adult caregiver in the paediatric site and finally move to the adult site.
107	Siegel, S. *et al.,* 1992	2	M	Education, USA	Youths with mild learning disabilities Age not specified (n = 105)	Internal evaluation of employment patterns of youths with mild learning disability who participated in transition programme	80% of participants in the programme were employed; however, much of this was part-time employment. More participants reported beneficial aspects of working than not.
108	Somerville, J., 1996	1	N/A	Health, UK	Young people with congenital heart disease Age not specified (No sample)	Description of transition unit	Continuity of care into adult services with the same staff working on both adolescent and adult wards which are both based on same floor of the hospital.
109	Steele, R.W. and O'Keefe, M.A., 2001	2	M	Health/Social Services/ Voluntary sector/ Vocational training, USA	Homeless young people Age 16–21 years (n = 106)	A prospective evaluation to determine the effectiveness of a health intervention programme for homeless and runaway youth	Drug dependency reduced from 41% to 3%, sexually transmitted diseases reduced from 60% to 7%. 59% completed Hepatitis B immunisation programme. 42% achieved employment.
110	Steinkamp, G. *et al.*, 2001	3	W	Health, Germany	Young adults with cystic fibrosis Age 18–33 years (n = 44)	Evaluation by postal questionnaire and interview of transition to adult centre	CF patients expressed a desire to meet the adult physician prior to transition. They also thought that staff on the ward and physiotherapists needed to improve their knowledge of CF.

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Ref. number	Author(s)	Item type	Strength of evidence	Location	Sample	Design and intervention	Findings and comments
111	Stern, L M., 1986	3	W	Health/Education/ Social Services, Australia	Young people with a disability Age 14–26 years	Questionnaire-based evaluation of a multidisciplinary advisory panel	The aim of the multidisciplinary panel was to provide advice and support about options available for employment, education and independent living. The study found that the young people wanted less formality and more follow-up by the panel social worker, which had since been implemented.
112	Stower, S., 1998	1	N/A	Health, UK	Hospitalised young people Age not specified (No sample)	Description of role of transition nurse practitioner	Role includes: management of policy, procedures and practice; provision of nursing care to children in adult areas; family support; developing communication links between adult and children's services.
113	Summary of Conference Proceedings, 1995	4	M	Health, International	Young people with chronic illness Age not specified (No sample)	Describes 4 models of transition service: disease-specific models, generic models, single-site models and primary care models	Recommendations: transition should start early; period of preparation; options should be explored; individualised; needs co-ordination between health care providers; needs to be adequately financed; staff need training for transition.
114	Telfair, J. *et al.*, 1994	3	M	Health/Education/ Social Services/ Voluntary sector, USA	HIV-positive and at-risk youth Age not specified (No sample)	Describes a model of care provision developed from 10 funded pilot projects	Five key elements of care provision comprise: peer-youth information dissemination; peer-youth advisory groups; peer-youth outreach and support; tightly-linked medical social support networks; active case management and advocacy.
115	Tenner, A.D. *et al.* 1998	2	M	Health/Education/ Social Services/ Voluntary sector, USA	HIV-positive and at-risk youth Age not specified (No sample)	Describes a case management-based model of care provision	Five key elements of model comprise: youth-specific HIV counselling; outreach; intensive case management; prevention services for at-risk youth; peer involvement.
116	Thomas, D.F. and Botterbusch K.F., 1997	3	S	Social Services/ Vocational training/ Education, USA	Young people with traumatic brain injury Age not specified (n = 149)	Prospective national study providing validation of vocational assessment protocol (VAP)	VAP includes 9 rating scales (3 clinical profiles, 2 demographic profiles + 4 vocational profiles). Reliability coefficients for all 9 scales, p <0.001.

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Ref. number	Author(s)	Item type	Strength of evidence	Location	Sample	Design and intervention	Findings and comments
117	Tisdall, E.K.M., 1994	4	M	Health/Education/ Social Services/ Voluntary sector, USA	Disabled young people Age not specified (No sample)	Discussion of how best to consider disabled young people and their transition to adulthood	Recommendations include involving young person in all decisions, recording decisions to ensure promises are delivered, leaving room for young person to change their mind as they move through transition period, empowering young person to make decisions and take responsibility.
118	Van Den Berg J.E. and Grealish, E.M., 1996	1	N/A	Health/Education/ Social Services/ Voluntary sector/ Private agencies, USA	Young people with complex special needs Age not specified (No sample)	Describes an intensive, inter-agency, case-managed service – the 'wraparound process'.	Key components: a community-based, family-centred, individualised, culturally competent approach which builds on existing strengths and supports. Outcomes evaluation emphasised.
119	Viner, R, 2000	4	W	Health, UK	Young people with chronic illness Age not specified (No sample)	Review of current knowledge regarding transition from paediatric to adult services	Recommendations: flexible approach to timing; preparation period and education programme; a co-ordinated transition process; personal introduction to adult care team; transition co-ordinator; active participation of all staff; financial support; primary care involvement.
120	Warnes, C A., 1995	1	N/A	Health, USA	Young adults with congenital heart disease Age 18–20 years (No sample)	Description of adult congenital heart disease clinic	Transition programme included: liaison between the paediatric and adult cardiologists; consultation with the adult cardiologist in the paediatric setting before moving to the adult clinic.

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Ref. number	Author(s)	Item type	Strength of evidence	Location	Sample	Design and intervention	Findings and comments
121	Wehman, P., 2001	4	M	Education/ Vocation training, USA	Young people with disabilities Age not specified (No sample)	A review of current knowledge regarding community transition planning	Recommendations: community involvement, including local businesses; post-secondary educational opportunities; proactive involvement of parents; acquisition of functionally relevant, real-life skills; opportunities for real work experience.
122	Wehman, P. and Brooke, V., 2001	4	M	Education/ Vocation Training, USA	Young people with disabilities Age not specified (No sample)	Discussion of vocational placements and careers	Emphasises importance of real-life work experiences based in the local community.
123	Westwood, A.T.R. *et al.*, 1999	3	W	Health, South Africa	Young people with cystic fibrosis Age 16–18 years	Cross-sectional survey of transition process	Identified a need for more continuity of care, postponement of transfer and failure to attend follow-up appointments.
124	Wilson, S. and Greenhalgh. S., 1999	2	W	Health, UK	Young people with diabetes mellitus Age 16–25 years	Evaluation of a young person's diabetes clinic, including follow-up of non-attenders	Feedback from the young people was found to be essential to determine whether their needs were being met as well as a non-judgemental attitude when non-attenders returned to the clinic. The study resulted in positive benefits for the young people and staff with clinics being well attended.

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125	Woods, E.R., 1998	4	S	Health/Education/ Social Services/ Voluntary sector, USA	Young people with HIV/AIDS, at-risk and homeless youth Age not specified (No sample)	Overview of 10 funded projects in HIV care for young people	Four models of care identified: youth involvement; outreach; case management and comprehensive continuum of care.
126	Woods, E.R. *et al.*, 1998	2	M	Health/Education/ Social Services/ Voluntary sector, USA	Young people with HIV/AIDS, at-risk and homeless youth Age 12–24 years (n = 1301)	Retrospective descriptive evaluation of the extent of health service use among young people in the programme	Youth involved in programme more likely to be referred to mental health and substance abuse services.

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