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# **Systematic review of transition models for young people with long-term conditions: A report for NHS Diabetes**

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**March 2013**



**NHS**  
*Yorkshire and the Humber*



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NHS Diabetes has provided the essential link between diabetes strategy and frontline service improvements for patients with diabetes in England. Through their integrated work programmes they provided national leadership and direction and support local teams working to champion good quality diabetes care. As part of the wider NHS structural changes, NHS Diabetes ceased to exist on 31 March 2013.

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## EXECUTIVE SUMMARY

For many young people with long-term conditions (LTCs), transition is based on a single transfer event from paediatric to adult care, rather than a planned and structured process taking into account young peoples' individual needs. This can have adverse consequences for both the long-term health of young people with LTCs and the health service. With this in mind NHS Diabetes commissioned Leeds Metropolitan University to undertake a systematic review, the aim being to provide an overall picture of the current situation in relation to transition services for young people with LTCs. The review questions were:

1. What models or components of models are effective in ensuring a successful transition process for young people with LTCs?
2. What are the main barriers and facilitating factors in implementing a successful transition programme?
3. What are the key issues for young people with LTCs and professionals involved in the transition process?

The systematic review drew on 29 published studies (including 16 systematic reviews) of transition from paediatric to adult secondary health care services for young people with LTCs. These were derived from an electronic search of databases from inception to August 2012.

### Key findings

The findings from the systematic review show there are various transition models and no single model was identified as the most effective. However, components of individual models that facilitate successful transition were evident.

Transition needs to be:

- Centred on young people and placed in the context of young peoples' lives and their changing circumstances;
- Age-appropriate and take into account young peoples' maturity, cognitive ability, need in respect of LTC, social/personal circumstances and psychological status, as well as inclusion of the whole family;
- A streamlined progression from paediatric to adult services as part of a planned and structured process embedded in service delivery;
- A multidisciplinary approach with involvement from professionals in general practice, community paediatricians/nurses, etc.

Transition needs to include:

- Self-management education as part of a specific education programme, incorporating an assessment of young people's self-management competencies, self-confidence and readiness to transition.
- Close collaboration between paediatric and adult services with designated transition clinics attended by paediatric and adult health care professionals (HCPs).
- A transition coordinator to maintain a link with young people and liaise with various health, education and social sectors.
- Participation of young people and their families with written and verbal communication between paediatric HCPs, adult HCPs and young people and their families.
- A consideration of young peoples' concerns regarding the transition process (feelings of abandonment on leaving the paediatric team and anxieties around acquiring a new

adult provider), lack of access to HCPs in adult care and differences in care between paediatric and adult services.

- The joint preparation of a young person's portfolio that moves with the young person, to alleviate young peoples' fears and provide reassurance that their new provider will have all the required information about their medical history, etc.
- Training of HCPs to treat young people with LTCs and to utilise effective interpersonal and communication skills.
- Resources to develop, maintain and evaluate transition programmes.

## **Recommendations**

The following recommendations are based on the review findings. They are important as an evidence base in terms of the ways in which the transition process needs to change to improve the continuity and quality of care for young people with LTCs and their long-term health outcomes.

### *Young people-centred*

Every transition programme needs to be built around timelines that are tied to individual young peoples' developmental stages and circumstances, rather than a rigid schedule devised to suit HCPs/organisations. The process should start as early as possible and be flexible taking into account young peoples' age, maturity, cognitive ability, need in respect of the LTC, social/personal factors and psychological support.

### *A planned and structured process*

A transition programme should be embedded in service delivery with a written protocol/'roadmap' detailing the steps involved, so that organisations, HCPs, young people and their families are fully aware of what transition entails. The process needs to include designated transition clinics attended by both paediatric and adult HCPs and orientation tours of adult clinics.

### *Self-management education*

Transition needs to be based on a continuous education programme through which young people receive education and skills training to equip them to take control and manage their condition. This should include an assessment of young people's self-management competencies, self-confidence and readiness to transition.

### *A transition coordinator*

There is a need for a nominated individual to take on the role of transition coordinator. Such a person is responsible for:

- overseeing the management and administration of the transition process;
- liaising with the various health, education and social sectors that need to be involved in the transition process;
- maintaining a link with the young person in order to ensure young peoples' care remains consistent.

The transition coordinator can help to alleviate any fears and concerns the young person has in relation to leaving paediatric care and moving to a new adult provider.

### *Multidisciplinary approach*

Transition needs to encompass inter- and intra- agency communication and coordination. Integrated primary care and social service involvement throughout the transition process is an important aspect of transition.

### *Collaboration and communication*

Close collaboration and documented communication between paediatric HCPs, adult HCPs and young people and their families is essential before, during and after transition. The creation of a young person's portfolio is advocated to ensure the new adult provider has all the required information about a young person's medical/life history. Young people and their families need to be involved in the preparation of the portfolio, participate in discussions and be provided with choices and appropriate information, in order that they can make informed decisions about their on-going care regimen.

### *Training of HCPs*

A greater emphasis needs to be placed on training HCPs to treat young people with LTCs and the importance of effective interpersonal and communication skills. These should form an integral part of undergraduate education and continuing professional development.

### *Resources*

Individual organisations across all sectors need to be committed to providing the necessary resources for developing, maintaining and evaluating transition programmes, in order that young people with LTCs and their families derive the maximum benefit from their transition experience.

A full report is available that includes the review methods and a full reference list, and which presents detailed findings from the review. The citation for the full report is: Kime, N., Bagnall, A-M. and Day, R. (2013) Systematic review of transition models for young people with long-term conditions: A report for NHS Diabetes. London; NHS Diabetes.



## 1. BACKGROUND

There are increasing numbers of children and young people with long-term conditions (LTCs). Coupled with the advances in health care ensuring that young people survive into adulthood, this means that more young people are moving, i.e. transitioning, from paediatric to adult services. This process of transition is defined as, “a purposeful, planned process that addresses the medical, psychosocial and educational/vocational needs of adolescents and young adults with chronic physical and medical conditions as they move from child-centred to adult-orientated healthcare systems” (Blum et al 1993). Importantly, it is much more than a single event involving a simple physical transfer from paediatric to adult care.

The experience of many young people, however, is unfortunately based on a transfer rather than a transition process, which has adverse consequences for both the long-term health of young people and the health service. For those young people for whom the transition process is poorly managed, a decline in health status often occurs. For example, in young people with type 1 diabetes (T1DM), there can be a marked deterioration in glycaemic control as young people come to terms with having to adjust to the increased responsibility for their care expected of them by adult services (Fleming et al 2002). The effect of this on the health service is an increased incidence of loss to follow-up, with young people who are dissatisfied with their transition process voting with their feet and electing not to attend adult appointments, as well as increased rates of emergency presentations in hospitals and diabetes-related complications (Nakhla et al 2009). This has led in recent years to an increasing awareness amongst health care professionals (HCPs) that something needs to be done to improve the transition process for young people with LTCs. Indeed, it is recognised as a critical area for service improvement as current practices are failing to meet the needs of young people and their families (Kennedy 2010). At present, however, there is no universally accepted transition approach in terms of patient satisfaction, cost-effectiveness or health outcomes (Machado et al 2010).

The most effective way to achieve a smooth and successful transition is the subject of enormous debate, not least because of the wide variation in LTCs and in the provision of current services across the country. A number of recent policy initiatives provide a context for transition services highlighting the significance of transition (DH 2006; DH 2008). Despite these, it still remains unclear to what extent services have adopted a transition programme and, in the case of those that have a planned process, exactly what these entail and whether or not they are successful. Various transition programmes have been reported, but as yet there is no model or template for how transition should be implemented. Identifying which models, or components of models, are effective in ensuring a successful transition process is, therefore, key to the long-term health of young people. Equally important is the identification of the barriers and facilitating factors in implementing a successful transition programme. Another factor that is becoming increasingly apparent from the literature is the recognition that transition is just one aspect of young people's lives and, therefore, needs to be placed in the broader context of their changing educational, social and psychological circumstances. This means it has to be a participative, flexible and supportive process (Brooks et al 2009). Equally, all professionals who have contact with young people with LTCs should be aware of the significance of the transition process, especially in terms of young people's health outcomes.

Previous reviews have largely concentrated on describing the issues surrounding transition and programme development. A few notable exceptions have focused on interventions in transitional care and examined the evidence for their effectiveness in improving health outcomes in a broad range of conditions (While 2004; Brooks 2009; Crowley 2011). These have identified the key features of transitional programmes in terms of service delivery,

barriers to transition and principles of successful transition, and have made recommendations for future service development. Increasingly, reviews are beginning to realise the importance of qualitative research in examining young people's transition experiences, both before and after transition has taken place, and their needs in terms of what they want from transition (Doug 2011; Lugasi 2011).

This review set out to bring together all the evidence in relation to the factors identified above, in order to provide an overall picture of the current situation in relation to transition services for young people with LTCs. Its particular focus was on transitional models, or components of models, that have been developed to manage the transition process and their effectiveness. This included the barriers and facilitating factors that needed to be adopted for a successful transition process, whether the models improved the outcomes for young people with LTCs and how the models were evaluated. Importantly, it also focused on the key issues for young people with LTCs and professionals involved in the transition process.

## **2. METHODS**

The systematic review was carried out according to established systematic review methodology (CRD 2009; Higgins and Green 2008).

### **Review questions**

The review aimed to answer the following questions:

1. What models or components of models are effective in ensuring a successful transition process for young people with LTCs?
2. What are the main barriers and facilitating factors in implementing a successful transition programme?
3. What are the key issues for young people with LTCs and professionals during involved in the transition process?

### **Inclusion criteria**

#### **Participants**

Studies that included young people aged 11 to 25 with LTCs (e.g. diabetes, renal disease, cardio vascular disease, cystic fibrosis and asthma), in transition from paediatric to adult secondary health care services.

#### **Interventions**

Studies examining both models and components of models of transition from paediatric to adult services in secondary health care, for young people with LTCs: models of transition were compared where applicable. Studies that compared transition processes to abrupt transfer were also included.

#### **Outcomes**

Studies were included if they reported at least one of the following outcomes:

1. Primary outcome measures were psychosocial measures such as wellbeing and quality of life, including young people's self-image and self-esteem.
2. Secondary outcomes included patient satisfaction; confidence and motivation to self-manage; compliance with treatment; biochemical markers associated with particular LTCs, e.g. HbA1c, FEV1 etc.; relevant longer-term outcomes (if reported); barriers and facilitating factors from process evaluations and key issues from qualitative evaluations.

#### **Studies**

We considered systematic reviews and primary research studies of transition from paediatric to adult secondary health care services for young people with LTCs. We considered any evaluations of models of transition from paediatric to adult services in secondary care for young people with LTCs: studies with and without a comparison group. We also considered any process evaluations of implementing models of transition from paediatric to adult services for young people with LTCs and qualitative studies of young peoples' (with LTCs) views of what the key issues are in transition care. Studies were published in English, but not restricted to the UK.

## Literature search

We searched the following electronic databases from inception to August 2012: MEDLINE, EMBASE, PsychINFO, CINAHL, ASSIA, Social Services Abstracts, Academic Search Complete and Web of Science- Social Science Citation Index. We also searched the Cochrane and Campbell Libraries.

For search strategy see Appendix A.

We screened reference lists of relevant reviews and identified studies. Recent conference proceedings were also screened.

## Study selection

Firstly, the inclusion criteria were piloted with a sample of the literature search results by three reviewers independently using a pre-agreed form. Two reviewers then independently selected the studies to be included in the review using titles and where available, abstracts. Disagreements were resolved by consensus between two reviewers and if consensus could not be reached, a full copy of the paper was ordered and the third reviewer was consulted if necessary. In the second stage of study selection, full papers were screened by two reviewers working independently, using the piloted study selection form. Disagreements were resolved by consensus, with reference to the third reviewer where necessary. Decisions were recorded in an Excel spreadsheet.

While screening the titles and abstracts, we made post-hoc decisions to exclude the following:

1. Any editorials and discussion or comment pieces or guidelines derived from expert consensus.
2. Studies of personal characteristics of young people that might indicate readiness for transition and studies of instruments to measure readiness for transition.
3. Studies that measure a clinical outcome such as transplant rejection after transition, but without details of the transition method or model.
4. Studies of transitions in social care, social services, mental health services (community based), education or foster care.
5. Studies detailing transitions to “adulthood” or transitions in primary care or studies of patients in “medical homes.”

After screening the full papers, we were left with 16 systematic reviews and 142 primary studies that met the inclusion criteria. After discussion with NHS Diabetes and in consideration of the timescale and funding available, it was decided to restrict the inclusion criteria to systematic reviews and primary studies which had been published after the latest systematic review for each review question (i.e. those primary studies which would not have been picked up by the literature searches for the included systematic reviews). Thus, this systematic review essentially became an updated systematic review of systematic reviews, and we followed established methodology for carrying out these “reviews of reviews” (Smith et al. 2011).

## Data extraction

After piloting standardised data extraction forms (see Appendix B) - one for systematic reviews and one for primary studies - data were extracted by one reviewer onto the appropriate form and checked by a second for accuracy. Data were extracted (where reported) from all papers on:

- population,
- age,
- sex,
- ethnicity,
- socioeconomic status,
- condition,
- stage of transition,
- setting,
- intervention/model/component,
- comparator if applicable,
- outcomes measured,
- findings,
- limitations and study designs,

and additionally from the primary studies: methods of data collection, costs/economic matters, any negative impacts and key process issues, barriers, facilitating factors and recommendations for successful transition.

## Validity assessment

One reviewer assessed the methodological quality of the included studies using a standardised validity assessment form; this was then checked by a second reviewer. Disagreements were resolved by consensus with reference to a third reviewer if necessary. Appropriate validity checklists were used for each study design (see Appendix C); two forms were used for assessing the validity of systematic reviews. The first was developed in-house to check the relevance and scope of the review against our review questions and the second to assess scientific rigour against current standards (Shea et al. 2007). The validity of primary studies was assessed using separate forms for qualitative and quantitative studies. The forms were adapted from existing sources: the EPPI-Centre for qualitative studies (Rees et al. 2009) and NICE Public Health Methods Guidance for quantitative studies (NICE 2009). One reviewer assigned a validity score to each paper based on the completed validity assessment forms. Systematic reviews were given a score out of 11, based on answers to the 11 questions asked in the form. Primary studies were given a score of 1-3 for methodological quality (or internal validity), with 1 representing high quality and 3 representing low quality studies. Primary studies were also given a score of 'a' to 'c' for relevance, with 'a' representing high relevance and 'c' representing low relevance.

## Data synthesis

A review of systematic reviews and primary studies that met the inclusion criteria was carried out and information extracted on key fields using a common data extraction framework (see Appendix B). A narrative synthesis approach was adopted, keeping data within the three review question headings and grouping by model or component and/or population group (e.g. long-term condition) according to how data was presented in the included studies.

Findings for each model of care were grouped and compared with other models, and against no planned transition. Prominence was given to evidence from well-conducted systematic reviews.

### 3. RESULTS

#### Overview of search results

The literature search retrieved 9,992 titles and abstracts (including duplicate records) and two further papers were identified from reference lists of included studies. After the first stage of screening, 9,662 of these were excluded and 332 retrieved for full paper screening. At this stage, 143 papers were excluded: 106 were not found to be reports of research studies; 16 were not about transitions in secondary health care; 14 did not report outcomes of interest to this review; 5 were about measuring readiness for transition or characteristics of young people that predict successful transition; 1 was not about young people and 1 was not about LTCs. A further 31 studies were unobtainable (see Appendix E for a list of excluded studies). The inclusion criteria were met by 161 papers: 16 systematic reviews and 142 primary studies. Due to the large number of systematic reviews, and the short timescale of the project, we excluded all 129 primary studies that had been published within the search period of included systematic reviews, only including those 13 that had been published later and, therefore, could update the information contained in the reviews. See Table 1 for a description of included studies and Appendix D for a list of included studies.

The methodological quality of the included systematic reviews and primary studies was, on the whole, poor. Systematic reviews scored a maximum of 6 out of 11 possible points, with most scoring 4 or less. Primary studies did a little better, with three (Gilliam, Michaelis and Wong) scoring 1 (high) for internal validity, and three (Michaelis, Valenzuela and Vijayan) scoring a (high) for relevance. However, four primary studies scored 3c (low validity and relevance).

The main problems with the included systematic reviews were:

- None of them indicated whether a protocol was developed (and preferably peer reviewed) before the review started.
- Few provided details of how any reviewers carried out each stage of the review (ideally two reviewers carry out study selection, data extraction and validity assessment).
- Lists of included and excluded studies were not provided.
- The methodological quality of included studies was not assessed.

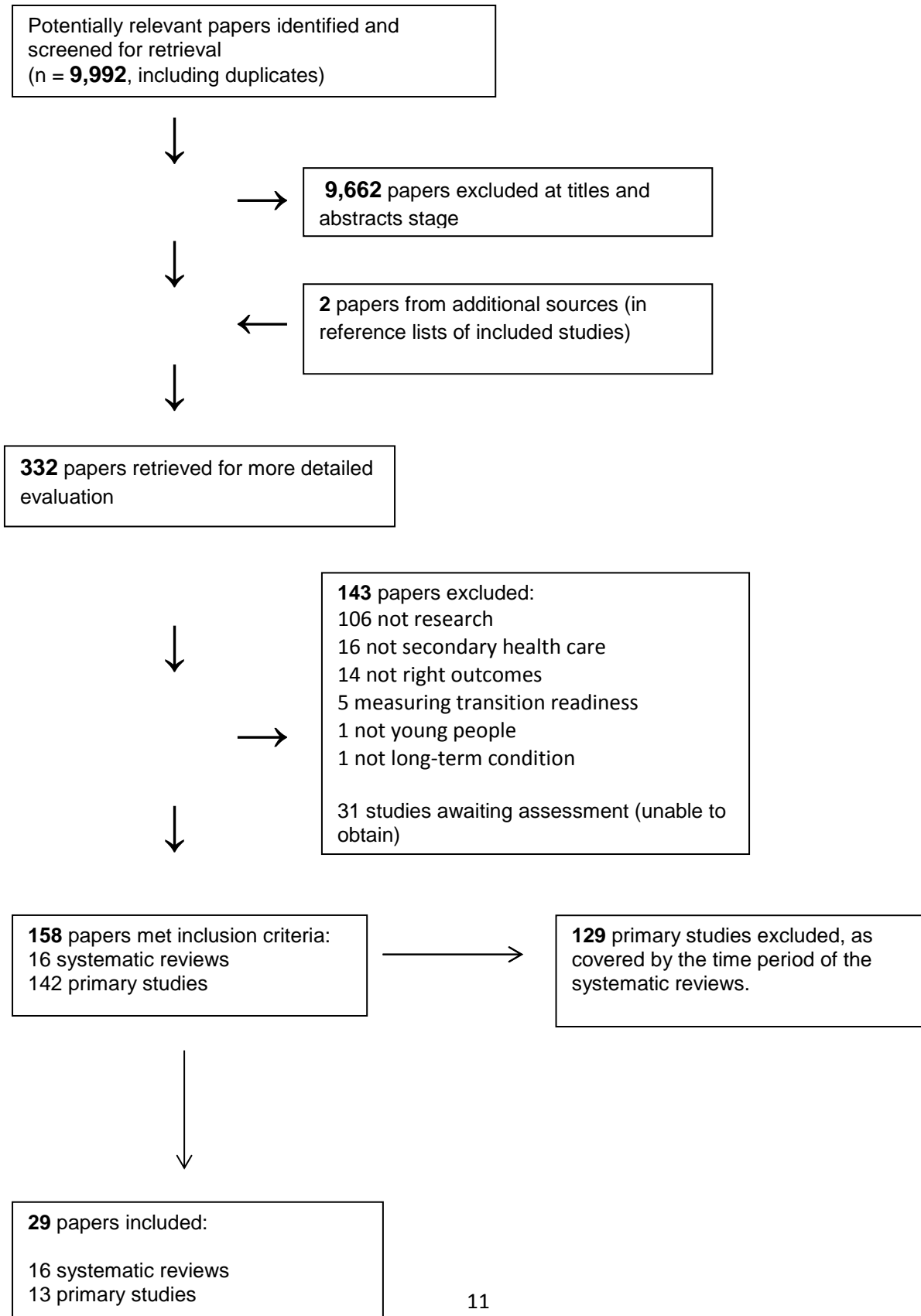
Most included systematic reviews did, however, undertake a comprehensive literature search.

The main problems with the included primary studies were:

- Lack of detail given on sampling/ selection of participants.
- Lack of detail given of data collection and analysis methods.
- Poor support given for findings of qualitative studies (possibly due to space restrictions).
- Unreliable outcome measures (in quantitative studies).

Completed validity assessment forms are available from the reviewers on request.

**Figure 1: Study selection process**





**Table 1: Included studies**

Bibliographical reference	Review question	Country	Study design	Population	Intervention	Outcomes	Validity
<b>SYSTEMATIC REVIEWS</b>							
BETZ, C.L. Issues in Comprehensive Pediatric Nursing 2004, 27: 179-241	1, 2, 3	n/a	Systematic review	No inclusion criteria stated; presumably adolescents with special health care needs.	No inclusion criteria stated; presumably transition services/ models/ programs/ planning.	No inclusion criteria stated.	3/11
BINKS, J.A., BARDEN, W.S., BURKE, T.A., and YOUNG, N.L. (2007). Arch Phys Med Rehabil, 8, 1064- 1072.	2	n/a	Systematic review	Young people with spina bifida and cerebral palsy, or other conditions previously experienced in childhood but now common in adulthood	Not specified.	<ol style="list-style-type: none"> <li>1. Barriers to transition</li> <li>2. Key elements suggested for transition programmes</li> <li>3. Empirical Evidence Related to the Process and Outcomes of Transition</li> </ol>	3/11
BROOKS, F., BUNN, F. and MORGAN, J. 2009. British Journal of Community Nursing, 14, 301-	1, 2	n/a	Systematic review	Not specified.	Transition programmes.	Generic issues that contribute to effectiveness in transition; Challenges and barriers; Recommendations.	3/11
COYNE, I.T., BREEN, M., DEMPSEY, O. and WHILE, A. 2012. Journal of Cystic Fibrosis, 11, S139.	2, 3	n/a	Systematic review	No inclusion criteria stated; probably young people with chronic illness, especially but not exclusively cystic fibrosis	No inclusion criteria stated; transition process	No inclusion criteria stated; probably experiences of young people, impacts on health and wellbeing, and process issues	1/11 abstract only
CROWLEY, R., WOLFE, I., LOCK, K. and MCKEE, M. 2011. Improving the transition between paediatric and adult healthcare: a systematic review. Archives of Disease	3	n/a	Systematic review	A wide age range was included (11-25 years) Children have chronic disease, mental illness or disability Countries not specified	Studies were included if they involved a health service intervention during the period of transition from paediatric to adult care. They evaluated changes in health outcomes following this transfer, and if outcomes were compared either between an intervention and control group or pre-intervention and post-intervention in a single group	Health outcomes: Disease specific biochemical indicators, such as HbA1c or creatinine, and/or health service use, such as percentage of missed follow-up appointments More robust outcome measures included hospital admissions for diabetic ketoacidosis or prevalence of diabetic complications (nephropathy, retinopathy, hypoglycaemia)	5/11
DILEK, Y., BERNA, F.E. and DILEK, K. 2011. Acta Paediatrica, International Journal	1, 3	n/a		Not specified; presumably, young people with chronic illness who have transitioned to adult health care.	Not specified; transition process?	Not specified.	1/11

DOUG, M., ADI, Y., WILLIAMS, J., PAUL, M., KELLY, D., PETCHHEY, R. and CARTER, Y.H. 2011.. Archives of Disease in Childhood, 96, 78-84.	1, 2, 3	n/a	Systematic review	Young people aged 13-24 years with palliative care conditions (defined by author's criteria) in the process of transition.	Other transition programmes/models	Not specified.	6/11
FLEMING, E., CARTER, B. and GILLIBRAND, W. 2002. Journal of Clinical Nursing, 11, 560-567.	2	n/a	Systematic review	Adolescents/young people with diabetes undergoing transition to adult health care	Not clearly specified.	Not specified in inclusion criteria, but: 1. The unique health needs of adolescents with diabetes 2. Transition from the children's health care service into the adult health care service 3. Barriers to the transition from the children's health care service into the adult health care service 4. Adolescents' perceptions of the transition into the adult health care system 5. Principles of a successful transition	2/11
JALKUT, M.K. and ALLEN, P.J. 2009. Pediatric Nursing, 35, 381-387.	1, 2, 3	n/a	Systematic review	Adolescents, young adults and adults with congenital heart disease	Transition care in CHD and other chronic conditions	Physiological and psychological outcomes	1/11
JONES, S.E. and HAMILTON, S. (2008) British Journal of Nursing, 17 (13), 842-847	1, 2, 3	n/a	Systematic review	Diabetes	Not clearly specified.	Gives an overview of issues, barriers and facilitators to successful transition and touches on models for transition of care.	2/11
LUGASI, T., ACHILLE, M. and STEVENSON, M. 2011. Journal of Adolescent Health, 48, 429-440.	2, 3	n/a	Systematic review	Focus on adolescents and /or young adults with a physical chronic illness  Excludes mental illness e.g. ADHD, autism learning disabilities or cognitive impairments	Not specified.	Examines patient's transition experience, before or after the transfer took place	4/11
MACHADO D.M, SUCCI R.C, and TURAT E.R.. Journal de Pediatria 2010; 86 (6): 465-72	1, 2	n/a	Systematic review	Not stated; presumably adolescents living with HIV/ AIDS	Not stated; presumably transition models	Barriers and recommendations for good transition practice.	1/11
NAKHLA, M., DANEMAN, D., FRANK, M. and GUTTMAN, A. (2008). Journal of Paediatric Endocrinology and Metabolism, 21 (6), 507-516	1, 3	n/a	Systematic review	Adolescents with diabetes undergoing transition	Different transition models within four health districts in Oxford UK region	Description of outcomes following transition including perceptions of the transition process and evaluation of the models of transition care	4/11
PAI, A. LH. and OSTENDORF, H.M. 2011. Children's Health Care, 40, 16-33.	2, 3	n/a	Systematic review	Adolescents and young adults affected by a chronic illness	Health care transitions	Treatment adherence	2/11
WATSON, R., PARR, J.R., JOYCE, C., MAY, C.L.E COUTEUR, A.S. 2011. Child:	1	n/a	Systematic review	Young people (14-25 years?) with cerebral palsy, autistic spectrum disorder	Models of transitional care: 'model' defined as clear description of new or existing	Not specified.	4/11

Care, Health & Development, 37, 780-791.				and diabetes, transferring from child to adult health services.	transitional care arrangements from child to adult healthcare services for young people aged 14-25 years.		
WHILE, A., FORBES, A., Ullman, R., LEWIS, S., MATHES L. and GRIFFITHS P. 2004. Child: care, health and development, 30, 439-452.	1, 3	n/a	Systematic review	Review focused on five tracer conditions at transition: diabetes mellitus, learning disability, cystic fibrosis, congenital heart disease and muscular dystrophy	Practices relating to continuity or management of transition, good practice models	Identifying practices Critically appraising practices Identifying the key components of good practice	3/11
<b>PRIMARY STUDIES</b>							
Betz, et al 2010. Int J Child Adolesc health, 3 (4), 595-607	3	USA	RCT	Spina bifida (SB), aged 14-18 years	Cognitive-behavioural programme of Transition Preparation Training (TPT), in combination with spina bifida management, compared to SB management alone.	1. Subjective Wellbeing (PARS II scale) 2. Role mastery (CLSS) 3. Self-care practice (DSCPI-90) 4. Transition questionnaire youth and parent versions.	3c
Cadario F, Prodam F, Bellone S et al. Clinical Endocrinology 2009; 71: 346-350	1	Italy	Retrospective Database analysis plus questionnaire and HbA1c measurements	T1DM	Structured transition planned with endocrinologists of the adult diabetes service.	Medical care during transition period; insulin prescriptions; frequency of physical examinations; assessment of glycaemia tests; retinal and foot screening; number of HbA1c determinations and microalbuminuria tests for year; last changes in insulin therapy (self-made or proposed by GP or endocrinologist). Patients' feelings about their diabetes care in PDS and their transition; HbA1c	3c
Clarizia et al 2009. Can J Cardiol, 25 (9), e317-e322	2, 3	Canada	Mixed methods: survey and interviews.	Patients aged 9 to 18 years with congenital heart defects and their respective parent(s)	No formal transition programme was in place at the time	Patient interviews: Patient's current knowledge; what topics the patient wanted to receive more information about.  Parent interviews: Knowledge of and concerns about the transition process, whether they perceived their child to be ready for transition. The extent of involvement in their child's care; beliefs about the roles of child, parent, nurses and physician in preparing their child for transition. Survey: opinions about transition preparation in the outpatient clinic, barriers to successful transitioning, what they currently do to prepare them and what they felt was necessary to prepare their patients more effectively.	3c

Collins SW, Reiss J, Saidi A. Journal of Hospital Medicine 2012; 7(4): 277-281	3	USA	Web-based survey	Paediatric hospitalists looking after children with a range of chronic medical conditions/ special health care needs	Various models.	<ol style="list-style-type: none"> <li>1. Who is responsible for the care of young adults and adolescents?</li> <li>2. Hospital-based transition services</li> <li>3. Benefits or challenges for paediatric hospitalists who become involved in health care transition.</li> <li>4. Knowledge of health care transition and education opportunities.</li> </ol>	3c
De Beaufort C, Jarosz-Chobot P, Frank M et al. Pediatric Diabetes 2010; 11: 24-27	1, 3	36 countries all members of ISPAD	Survey	Health care practitioners of various disciplines working in the transition of youth with T1DM.	Study collects data about practices of paediatric diabetes health care practitioners in different parts of the world concerning transition from paediatric to adult diabetes care.	Demographics; Transition process: e.g. where and at what age youth are transferred to adult care, who initiates referral, how formalised is the process, how many youth make a successful transition etc. Opinions of participants regarding ideal age for transition and suggestions for improving transition process.	2b
Fernandes SM, Fishman L, O'Sullivan-Oliveira J et al. Int J Child and Adolescent Health 2010; 3 (4S): 507 - 515	1, 3	USA	Web-based multiple choice survey	A randomised sample of physicians, nurse practitioners and nurses who were likely to provide care to patients over the age of 11 years in the outpatients setting, plus all social workers and physician assistants	Various models	The final survey included a list of 25 questions within the following six categories: <ol style="list-style-type: none"> <li>1. Inclusion criteria</li> <li>2. Self-management (transitioning) skills assessment and education</li> <li>3. Transfer to an adult-orientated health care system</li> <li>4. Demographics</li> <li>5. Age-appropriate care resources</li> </ol>	2c
Gilliam P. 2009. Graduate School Theses and Dissertations.	1	USA	Semi-structured interviews, and review of clinic documents.	HIV-infected adolescents.  Interviews were conducted with 19 staff members: 7 social workers, 7 nurse practitioners, 3 physicians, 1 registered nurse, 1 health educator from 14 ATN clinics.	Various models.	<ol style="list-style-type: none"> <li>1. How do health care team members view transition?</li> <li>2. What do health care team members perceive as facilitators to a successful transition to adult care?</li> <li>3. What do health care team members perceive as barriers to a successful transition to adult care?</li> <li>4. What are the similarities and differences among the clinics that have a structured transition program and those that do not?</li> <li>5. What strategies have ATN systems of care developed to assist patients in making a successful transition to adult medical care?</li> </ol>	1b
Irvine T, Srinivasan R, Casson DH et al. Gastrointestinal Nursing 2010; 8 (7): 19-25	1, 3	UK	Survey	Young people (adolescents) with inflammatory bowel disease who had been through the transition process between Alder Hey and RLUH from 2003 – 2008.	Structured approach to transition compared to general approach to transition.	Patient information; Patient satisfaction; Suggestions; Subjective comments.	2b

Michaelis A (2009) PhD thesis, Baltimore, Maryland	1, 2, 3	USA	Qualitative	Study aims to explore facilitators and barriers to successful transition from paediatric to adult medical care for those youths living with HIV.	37 (21 female and 16 male) HIV infected youth aged 18-24 still in receipt of paediatric care and not yet begun the transition process to adult care.	<ol style="list-style-type: none"> <li>1. Youths' experiences and self-perceived needs related to transitions from adolescence to adulthood and related to transitional medical care.</li> <li>2. Attitudes and practices of paediatric and adult medical providers specialising in HIV care in relation to transitioning patients.</li> <li>3. Types of clinic-based intervention strategies that are useful for facilitating successful transitions.</li> <li>4. The barriers to successful transition from paediatric to adult medical care for youths living with HIV.</li> </ol> <p>Successful transition clinics' common outcomes.</p>	1a
Valenzuela JM, Buchanan CL, Radcliffe J et al. Journal of Pediatric Psychology 2011; 36 (2): 134-140	3	USA	Qualitative study	Adolescents/ young adults older than 18 years, with behaviourally acquired HIV, previously treated at the adolescent clinic for at least 1 year within the prior 5 years,	All participants had previously been treated at the same HIV clinic in a paediatric hospital with interdisciplinary primary and HIV speciality care for adolescents.	<ol style="list-style-type: none"> <li>1. How does your adult HIV care experience compare to your previous paediatric experience?</li> <li>2. What helped you during your transition</li> <li>3. What are some things that have made it harder to transition from paediatric to adult HIV care?</li> <li>4. What changes would you like to see in place in order to create the ideal transition experience for other young adults with HIV?</li> </ol>	2a
Vijayan et al 2009. AIDS Care, 21 (10), 1222-1229.	2, 3	USA	Qualitative study	Adolescents who: 1. Had vertically transmitted HIV 2. Did not have a clinical diagnosis of substantial cognitive limitation 3. Were 12-24 years old	Yale Paediatric AIDS Care Programme - they aimed to describe the challenges to caring for adolescents with perinatally acquired HIV infection and the barriers to transitioning them to adult-orientated healthcare settings.	Outcomes from interview not specifically stated History of sexual activity and drug use – used confidential written questionnaire	2a
Wiener LS, Kohrt BA, Battles HB, Pao M. Journal of Pediatric Psychology 2011 36 (2) 141-154	2	USA	Qualitative, with a quantitative analysis of CD4 counts	Young adults or adolescents aged 18+ were recruited for the study and asked about their experience of transition to adult HIV care.	Participants had been enrolled on clinical trials at 'a large medical research facility' when administrative decisions were made to close the programs. They were then transitioned in their 'home community'	<p>Questions pertained to:</p> <ol style="list-style-type: none"> <li>1. Current health status and medication regimens,</li> <li>2. Whether participant had medical insurance</li> <li>3. If transition to adult care had occurred, whether the transition was as expected, better than expected or more difficult than expected.</li> </ol> <p>Participants were also asked whether they had faced any challenges or difficulty obtaining services or adhering to a medication regimen or schedule since the transition occurred. Physical health status was measured by participants' CD4 count obtained during</p>	2b

						their last clinic visit prior to program closure and self-report of their most recent CD4 count.	
Wong L, Chan F, Wong F, Wong E, Huen K, Yeoh E, Fok T (2010) Transition care for adolescents and families with chronic illnesses. Journal of Adolescent Health 47: 540-546.	2, 3	Hong Kong	Quantitative cross-sectional study	Adolescents with a chronic disease requiring long-term follow-up at the pediatric clinic, and who were likely to have their diseases extending into adulthood, together with their parents, were recruited from a regional hospital in HK.	Self-administered questionnaire to explore attitudes of adolescents with a chronic condition and parents towards transition care and to identify factors and barriers associated with transition decision in Hong Kong.	Participants' perceptions of transition care. Perceived severity and chronicity of adolescents' health problem, Perceived physician's effectiveness, Attitude toward transition care, Factors and barriers affecting transition decision, Demographics including age, gender, education level, family structure, socioeconomic status, parental education. Participants also invited to give suggestions re. how to implement smooth transition.	1b
Young N, Barden W, Mills W et al. Physical and Occupational Therapy in Paediatrics 2009; 29 (4): 345-361	2, 3	Canada	Qualitative	15 youths (14-18 years) and 15 adults (24-32 years) with cerebral palsy, spina bifida and acquired brain injuries of childhood. Plus 30 caregivers.	Exploration of transition to adult-oriented health care in a Canadian context.	Anticipation or experience of health care transition. Factors affecting outcome of transition.	2b

**Review question 1: What models, or components of models, are effective in ensuring a successful transition process for young people with long-term conditions?**

Twelve studies contained information relevant to review question 1: six systematic reviews (Crowley 2011, Dilek 2011, Doug 2011, Jones 2008, Machado 2010, Nakhla 2008, While 2004) and six primary studies (Betz 2010, Cadario 2009, Collins 2012, De Beaufort 2010, Fernandes 2010, Irvine 2010,).

*Table 2 Long-term conditions covered in review question 1*

Diabetes	4 studies: Jones 2008; Nakhla 2008; Cadario 2009; De Beaufort 2010
Unspecified LTCs	2 studies: Collins 2012, Fernandes 2010
HIV/ AIDS	1 study: Machado 2010
Congenital heart disease	1 study: While 2004
Spina bifida	1 study: Betz 2010
Learning disability	1 study: While 2004
Muscular dystrophy	1 study: While 2004
“Palliative care conditions”	1 study: Doug 2011
Cystic fibrosis	1 study: While 2004
Inflammatory bowel disease	1 study: Irvine 2010

None of the primary studies were of high validity or relevance. All of the evidence for review question 1 was of low to moderate validity.

Included studies did not contain much evidence on whether models were effective, but were more focused on describing the models and/or what components of the models did or did not work.

*Models*

Evidence from systematic reviews:

Doug 2012 found that different transition models or processes were proposed for different conditions, which they grouped as: life threatening conditions; life-limiting conditions; severe non-progressive neurological disability; mixed palliative care conditions and generic transition strategies.

Crowley 2011 identified three broad categories of intervention: directed at: the patient (educational programmes, skills training); staffing (named transition coordinators, joint clinics run by paediatric and adult physicians) and service delivery (separate young adult clinics, out-of-hours phone support, enhanced follow up).

The following models were identified:

*Service delivery focused*

1. Direct transition from paediatric to adult service (Doug 2012, While 2004, Nakhla 2008) in the same hospital.
2. Transfer to a young adult clinic within the same hospital with introduction to the adult physician prior to transfer (Nakhla 2008).
3. Transition from paediatric service to adolescent clinic to adult service (Doug 2012).
4. Transition from paediatric service to adolescent clinic to young adult clinic to adult services (Doug 2012).
5. Transfer to a young adult clinic in a different hospital (Nakhla 2008).
6. Transfer to an adult clinic run jointly by paediatric and adult physicians (Nakhla 2008).

#### *Patient/ provider focused*

1. Condition-specific model (e.g. cancer, cystic fibrosis). Doug 2012 identified this as the most prevalent model.
2. Sequential transition model – recognises that young person's needs are changing and they require some preparation to adjust to adult care successfully. This may involve a re-defining of the family role with the young person being given increased autonomy in decision-making about their care (While 2004). Jones 2008 reported that this model was the most appropriate for diabetes, although they acknowledged that no empirical studies of the model have been published.
3. Developmental transition model – starts from the premise that the young person will need some help in acquiring the skills and support systems necessary with adult care; this is most relevant regarding services for vulnerable young people and those with physical disabilities or learning difficulties (While 2004).
4. Professional transition model – focuses on how 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 is important in conditions with a short life expectancy or where expertise is heavily located within one service, e.g. cystic fibrosis, HIV/ AIDS (While 2004).

#### *Survey findings*

De Beaufort 2010 surveyed all 578 members of the International Society for Paediatric and Adolescent Diabetes (ISPAD) and found that in 76% of the centres young people are seen until the age of 18 years, 36% of paediatric centres see adults over 25 years, most children under 12 (87%) are seen by a paediatric diabetologist and half of centres reported having a structured transition programme targeting youth aged 16-25 years.

Fernandes 2010 surveyed clinicians at a children's hospital in Boston (Fernandes 2010) and found that 73% stated their patients received transitioning (self-management) skills assessment/education. 58% indicated that such skills assessment was provided by the clinician and other members of their team. 92% indicated that transitioning (self-management) skills assessment and education were usually provided in an informal fashion. Most providers stated that they began their transitioning assessment in mid-adolescence. 64% felt that there should be a specific programme within their department to provide



education and assessment of transitioning (self-management) skills. 95% agreed that there should be a process to streamline the transfer of patients to an adult-oriented healthcare system. The majority thought their institution should provide resources for the development of such programmes.

Collins 2012 found that 60.9% of participants did not know if their hospital had inpatient-oriented healthcare transition services. 27.8% only had informal or unstructured services for some patients with a chronic condition and less than 1% had a formal or structured transition programme at their institution (for any chronic medical condition). 80% thought transferring adolescent or young adult patients from paediatric to adult providers was a moderate to major problem. 97.6% felt that inpatient-oriented healthcare transition services would be beneficial to adolescent and young adult patients and 92.2% felt that these supports would be beneficial to paediatric providers. Nearly 40% of institutions have a mandated age by which adolescent and young adult patients must be transferred to adult providers and facilities. Only 5.2% of these institutions have a written protocol to describe the transition process. 68% believe that patients' primary care provider is the most qualified to discuss healthcare transition issues, followed by their paediatric subspecialists. However, more than 75% of respondents agreed or strongly agreed that paediatric specialists should be involved in providing healthcare transition services and support to in-patients with chronic health conditions. 58% are rarely, if ever asked to participate in healthcare transition by their subspecialist counterparts. Potential benefits to paediatric specialist participation in transition: improved communication between paediatric and adult providers and facilities (23%); better continuity of care in the inpatient setting (21%) and better quality of care for adolescents and young adults with chronic healthcare conditions (21%).

#### *Specific models described in primary studies*

Betz 2010 looked at a cognitive-behavioural programme of Transition Preparation Training (TPT), in combination with spina bifida (SB) management. The TPT Programme was a 3-module, 8-session programme offered in a 2-day workshop format that involved the development of an adolescent-centred transition plan (Transition Roadmap to the Future) based on a comprehensive assessment of the adolescent's goals for the future. No significant differences were found between groups for the following outcomes:

#### Subjective wellbeing

- Role Mastery
- Self-Care Practice
- The Transition Questionnaire Youth and Parent Versions (TDQ) (developed by the investigators).

Irvine 2010 tested the following structured approach: to introduce the concept of transition by age 13-14 years; to time transition as per individual patient needs and a 'pre-handover' meeting at the paediatric hospital for the families to meet the new adult team with the paediatric team present. This meeting was an open forum and an opportunity for individual case discussion, queries and support before transfer. The approach included: a comprehensive clinical summary from the paediatric hospital to the adult hospital before transfer; first hospital appointment at the adult centre with the paediatric team in the clinic

room providing an interactive handover; handover to adult services at the end of the clinic appointment and continued support as desired in individual instances.

Irvine found that 33/35 patients were satisfied or very satisfied with meeting the adult team prior to seeing them at the handover clinic ( $p < 0.0001$ ); 31/35 felt they were given enough information about the move ( $p < 0.0001$ ); 30/35 felt they had an opportunity to discuss change ( $p < 0.0001$ ); 22/35 felt the pre-transfer meeting reduced their anxiety about transfer ( $p < 0.0877$ ); 31/35 felt the right people were present at the first adult appointment ( $p < 0.0001$ ); 32/35 found it fairly or very helpful to have members of the paediatric team at the first adult appointment ( $p < 0.0001$ ).

Cadario 2009 evaluated the model of patients discharged at the end of adolescence with a structured transition programme planned with endocrinologists from the adult diabetes service (ADS). A single patient coordinator, qualified as a paediatric expert in diabetes, followed the patients during their paediatric care and into the transition programme working with the same endocrinologist. In the structured programme, eligible patients were informed about the transition during their last year in the paediatric diabetes service (PDS), with clear explanations about the process and clinical implications at each visit. The last visit in PDS for each patient was done jointly with the endocrinologist from the ADS without the presence of patients' parents. The paediatrician also gave a letter and a file to both the adult endocrinologist and then transferred patients. The first visit in ADS was done in the presence of the paediatrician and the adult endocrinologist, but the formal prescription was given by the adult endocrinologist.

When compared with patients who had a structured transfer, the unstructured group were more likely to have a break in clinical examinations (55.5% vs. 0,  $p < 0.001$ ) and laboratory examinations (74.1% vs. 0,  $p < 0.001$ ) during the transition period. While both groups rated their experience in PDS as good, all subjects in the structured transition group reported favourable judgement for the structured transition, compared to poor opinion for the unstructured transition in 19 out of 27 (70.3%) patients ( $p < 0.001$ ). One year after transition from PDS, 31% (10/32) of patients in the unstructured transfer group and nearly 100% (29 out of 30) of patients in the structured transition group were entered into ADS care. Three years after their last visit in ADS, 73% of patients in the unstructured and 100% of patients in the structured transition group were still followed in ADS ( $p < 0.05$ ). The first HbA1c in ADS was improved in the structured transition group compared to the mean of HbA1c in their last year in PDS (7.9 +/- 1.0% vs. 9.1 +/- 0.4%,  $p < 0.01$ ) (this was just after the transition period and without any change in prescription in the ADS), while there were no changes to HbA1c in the unstructured transfer group (8.4 +/- 1.3% vs. 8.9 +/- 0.8%,  $p = n.s.$ ). One year after the transition period, the mean HbA1c was lower in the structured than the unstructured transition group participants (7.8 +/- 0.5% vs. 8.9 +/- 0.5%,  $p < 0.1$ ). One year after the transition process there was a significant decrease in HbA1c levels in the structured transition group, while a trend towards an increase was observed in the unstructured transfer group; three years after the transition process similar levels were observed in both groups. Three years after the transition to ADS, there was a significant reduction in the clinical attendance in the unstructured transfer group compared with the structured transition group, despite a similar compliance in the last year in PDS care (57 +/- 5.0 vs. 80 +/- 12.5%,  $p < 0.05$ ).

### *Successful components of models from systematic review*

Crowley 2011 reported that all six interventions that resulted in significant improvements were in studies of patients with diabetes. Improvements were seen in HbA1c levels, acute and chronic complications, clinic attendance rates, self-management skills, disease specific knowledge and rates of screening for complications. They commented the most commonly used strategies in these successful programmes were patient education and specific transition clinics (either jointly staffed by paediatric and adult physicians or dedicated young adult clinics within adult services).

Nakhla 2008 noted there was no consensus on the most appropriate method of transition, but improvement in clinic attendance may be achieved through implementing an educational transition programme, having a transition care coordinator and ensuring a young adult transition clinic is attended by both the adult and paediatric physicians.

Machado 2010 also found little evidence supporting any specific model of health care transition, but noted several study authors agreed transitioning adolescents to adult-oriented healthcare should be a gradual process not determined by age alone. It requires a plan established with ample dialogue among adolescents, their families and paediatric and adult care teams.

### *Role of the transition coordinator*

Evidence from systematic review:

Jones 2008 looked at the role of the transition coordinator as a possible element of a transition structure. They reported nurses often take on this role and the administration behind transition is unlikely to occur without a designated coordinator. They reported professional medical societies recommend the appointment of a coordinator for each patient going through the transition process.

## Review question 2: What are the main barriers and facilitating factors in implementing a successful transition programme for young people with long-term conditions?

Nineteen studies contained information relevant to review question 2: ten systematic reviews (Betz 2004, Binks 2007, Brooks 2009, Coyne 2012, Doug 2011, Fleming 2002, Jalkut 2009, Jones 2008, Machado 2010, Pai 2011) and nine primary studies (Clarizia 2009, Collins 2012, De Beaufort 2010, Fernandes 2010, Michaelis 2009, Vijayan 2009, Wiener 2011, Wong 2010, Young 2009).

*Table 3: Long-term conditions covered in review question 2*

Diabetes	<b>3</b> studies: De Beaufort 2010; Fleming 2002; Jones 2008
Unspecified LTCs	<b>6</b> studies: Betz 2004; Brooks 2009; Collins 2012; Fernandes 2010; Pai 2011; Wong 2010
HIV/ AIDS	<b>4</b> studies: Machado 2010; Michaelis 2009; Vijayan 2009; Wiener 2011
Congenital heart disease	<b>2</b> studies: Jalkut 2009; Clarizia 2009
Cerebral palsy/spina bifida/ acquired brain injuries of childhood	<b>2</b> studies: Binks 2007; Young 2009
“Palliative care conditions”	<b>1</b> study: Doug 2011
Cystic fibrosis	<b>1</b> study: Coyne 2012

One of the included studies was of high validity (Michaelis) and the rest of the included studies for review question two were of low to moderate validity. In the following sections, the strongest evidence is presented in bold type.

### Barriers

Service/provider issues:

- An absence of a structured transition programme, lack of adequate resources/time/guidelines in relation to transition planning, limited transition information for distribution and unfamiliarity with transition resources, organisations failing to prioritise/support the process (Betz 2004, Binks 2007, Brooks 2009, Collins 2012, de Beaufort 2010, Doug 2009, Machado 2010, Michaelis 2009), difficulties accessing community resources (Betz 2004).
- Poor inter- and intra-agency coordination from the perspective of professionals, gaps in levels of integration between sectors in the health care system, lack of communication between paediatric and adult physicians and other adult care services in the community (Betz 2004, Brooks 2009, Jones 2008, Machado 2010, Michaelis 2009, Weiner 2011).
- Rigid policies and protocols that create inconsistencies. The model least likely to meet young peoples’ needs sees transition as a single transfer event to an

unfamiliar clinic with completely new professionals, whose views on the management of the condition are different from their previous practitioners' views (Brooks 2009).

- **Significant differences in care between paediatric services (supportive, family-centred approach; paediatric staff have more time and flexibility) and adult-oriented services (independence expected; adult staff have less time and flexibility because of bigger caseloads) and also within paediatric and adult services (Doug 2009, Machado 2010, Michaelis 2009).**
- Abrupt transfer to adult services with little or no prior preparation, poor or absent planning, poor preparation on the part of adult-orientated services to receive and treat young adults with childhood-onset chronic conditions, fragmentation and poor continuity of care, delay in booking appointments at adult clinic after transfer from paediatric service (Betz 2004, Doug 2009, Machado 2010).
- Unsatisfactory provider care (time constraints, lack of transition training and experience with childhood chronic illnesses, discomfort in talking about personal topics such as sex and drugs (lack of sexual health care resources) and discussing end of life issues or disability, difficulty accessing resources and difficulty communicating with adult providers (Betz 2004, Doug 2009, Jalkut 2009, Vijayan 2009).
- Resistance on the part of paediatric care providers (Fleming 2001, Machado 2010); providers' attachment to the family and reluctance to "let go" of their long-standing relationships with patients and distrust of adult-centred health services (Binks 2007, Fernandes 2010, Vijayan 2009, Weiner 2011).

#### Parental issues:

- Parents' and young peoples' emotional attachment to the institution/paediatric providers and difficulty "letting go" (Binks 2007, Vijayan 2009, Wong 2010).
- Unreliable histories, excessive dependence, high risk histories, confusion regarding extent of responsibility and "letting go" (Betz 2004, Clarizia 2009).
- Resistance of more marginal role they are expected to play in adult consultations (Betz 2004, Coyne 2012) and feeling they are excluded from the decision-making process because adult-centred services rarely engage with families in the same way as child-centred services (Binks 2007).
- Parents who impede the development of confidence and independence in young people by not allowing them to take an active role in their own care (Betz 2010, Clarizia 2009); paediatricians who enable this type of involvement because they do not feel parents are obstacles to transition preparation (Clarizia 2009).

#### Young person issues:

- Age, maturity and emotional/cognitive ability at transition (Betz 2004, Fernandes 2010, Jalkut 2009, Pai 2011, Weiner 2011).
- Knowledge of condition and care/treatment (Betz 2004, Jalkut 2009, Vijayan 2009).
- Psychosocial/psychological situation (Betz 2004, Jalkut 2009, Pai 2011).
- Reluctance to leave the safety and familiarity of family-centred care (Betz 2004, Binks 2007, Vijayan 2009, Weiner 2011).

- Challenge of learning to trust all over again (Weiner 2011).
- Young people expected to take responsibility for transferring to adult healthcare providers (Jones 2008), lack of support from paediatric and adult subspecialists (Collins 2012, Wong 2010) and lack of professionals' knowledge (Young 2009).
- **Young people feel unprepared to step up to tasks expected of them as young adults, in particular role change from passive to proactive health consumer (Michaelis 2009)** and taking the lead in their care/treatment (Coyne 2012).
- Uncertainty and lack of information regarding transition process (Wong 2010, Young 2009).
- Lack of access to HCPs and access to specialist and allied health professionals due to age limit, i.e. after age 18 criteria imposed by paediatric health services (Young 2009).
- Young people showed lack of adherence with following through their transition plan and others were unclear as to what actions they needed to undertake based on their plan (Betz 2010, Pai 2011).
- **Negative impressions of/unfamiliarity with adult clinic environment (Michaelis 2009, Wong 2010).**
- Need for more personal and consistent care (Weiner 2011).
- For those young people with HIV, perceived increase in stigma on transitioning to adult care (Vijayan 2009, Weiner 2011).
- For those with HIV, difficulty with adherence to medication regimen. Non-compliance due to fear of disclosure, i.e. taking medication in the presence of others. Act of taking medication was a negative reminder of the disease. Many young people depended on parents to help them take medication. Failure to take medication when feeling well (Vijayan 2009).
- For those with HIV, difficulty with adolescent sexuality. Young adults often unable to disclose HIV status to intimate partners; this presented a significant public health challenge to providers (Vijayan 2009).
- For those with HIV, disorganised social environments. This affected young people's emotional and psychological wellbeing, their perception of the disease and their adherence to their medication regimen (Vijayan 2009).

### **Facilitating factors/recommendations**

Doug 2012 reported the three principles that underpin a successful transition programme are information, communication and planning/coordination.

Dilek 2011 recommended in order to achieve a high quality, coordinated service the aims of transitional care should be a service that is: patient-centred; developmentally appropriate; responsive and comprehensive; promotes skills in communication, decision-making, assertiveness, self-care and self-advocacy; maximises life-long functioning; enhances sense of control and interdependence.

Brooks 2009 found the majority of included literature adopted the following key principles/traits when considering transition: participative; holistic; supportive; evolving; inclusive and collaborative.

The following factors were also identified as ensuring a successful transition process for young people with LTCs:

### ***Information***

Developmentally appropriate education for young people should begin as early as possible (Clarizia 2009). Differences between paediatric and adult care need to be identified and on-going guidance given about what to expect (Jalkut 2009). Successful transition programmes should include orientation tours and information provision (Coyne 2012). Information is important and more written and verbal information should be available relating to the transition process, available services, disease-related resources and expectations for the future (Jones 2008, Binks 2007, Young 2009, Pai 2011). Too much information too soon may not be well understood, but the opportunity to revisit the information and discuss it, perhaps by telephone, was helpful. Adolescents asked for the opportunity to visit the adult clinic, or for the adult team to meet jointly with the patient and paediatric team before transition. There was a recommendation by nurses for paediatric back-up to overlap and continue until the patient was securely transferred to adult services (Jones 2008).

**Wong 2010 found that “detailed explanation by doctors” encouraged transition related decisions for adolescents. Appropriate transition information, adequate time to prepare for transition, psychological preparation before transition and temporary transition care at a combined paediatric-adult clinic showed no significant effect. No significant factor was found facilitating parents to make transition related decisions. Information throughout the transition process should be directed at youths and not solely at parents (52%) (Young 2009).**

### ***Communication***

There needs to be increased continuity and quality of care. It is important to have a rapport with the doctor or healthcare team. Patients wanted a continuation of individualised care that they received as paediatric patients; seeing the same doctor each time would help. There needs to be improved communication between all parties involved in transition: between paediatric and adult providers; between patients and paediatric providers and between adult providers and primary caregiver/parents (Wiener 2011).

Good communication and connections between paediatric/ adolescent and adult providers/ services are a requirement (Machado 2010) and should be timely (Jones 2008) and documented (Jalkut 2009). Communication between paediatric and adult services was identified as central to achieving a coordinated and planned transition process. Aspects of good communication include: key worker role within adult services; a full multi-agency assessment that provides a structure for future communication, as well as establishing systems for joint working and communication; a system that ensures all young people's notes are transferred (Brooks 2009).

There needs to be provision for ample dialogue between paediatric and adult HIV care teams and the preparation of patients and their families via specific transition plans and robust support structures that address stigma, limited autonomy and the many other challenges to growing up with HIV (Vijayan 2009).

Professionals need to acquire additional skills and knowledge in working with young people, e.g. communication skills and understanding the physiology of adolescence (Brooks 2009).

### ***Preparation/ planning***

**Early communication and preparation for transition starting in early adolescence (Jalkut 2009, Michaelis 2009) and spread over a longer period of time (De Beaufort 2010, Michaelis 2009) is needed**, including a time period when both adolescent and adult care providers are being seen; options and control in the process and assistance with coordination and linking of services should be provided (Valenzuela 2011).

**Skill-building in preparation for adult care needs to occur regularly during medical and social work appointments (Michaelis 2009).**

Referral should be accompanied by a written summary of the paediatric experience and medical situation (De Beaufort 2010).

Youth should be prepared for changes in the atmosphere in adult settings. A different population and atmosphere can increase anxiety (Wiener 2011).

Transition programmes should have an individualised preparation period that includes age-appropriate information and visits to adult services (Brooks 2009).

Transition planning should be regarded as an essential component of care quality in adolescent-oriented services (Machado 2010, Pai 2011).

### ***Support***

Having the support of the paediatric subspecialists and the paediatric primary care provider is critical to successful transition (Collins 2012). **Post-transfer planning and monitoring should be included, incorporating strategies to make the paediatric team's withdrawal of support more gradual for patients. Support needs to be provided to youths for 6-12 months after they make the transition to adult care with a policy in place for those youths who fail to make a successful transition (Michaelis 2009).**

More extensive support (from HCPs, family, friends, etc.) throughout the clinical transition process- before, during and after is recommended (Young 2009). There needs to be a strong social support system, uninterrupted health insurance benefits, a transportation system and stable housing (Jones 2008). The following support mechanisms also need to be considered: counselling and psychosocial support; family support; advocacy; and peer/local support (Betz 2004). With almost 10% of the total cohort reporting having had a psychiatric hospitalisation over the past 3 years, the availability of mental healthcare appears to be a critical component for a successful transition (Wiener 2011).

### ***Patient readiness/characteristics***

Criteria:

Betz (2004) identified the following criteria used in transition: age (the most frequently cited ideal age was 16-22 years); physiologic status of special health care need or disability; presence of other problems; administrative issues; physician decision; marriage; pregnancy and knowledge of condition.



Fernandes 2010 reported that the most common patient characteristics endorsed by physicians as reasons to transfer a patient to an adult-oriented healthcare system were age (79%), presence of adult co-morbidities (78%), graduation from college (67%), pregnancy (58%) and marriage (56%). The use of alcohol or illicit drugs (29%) and graduation from high school (16%) were less likely to prompt transfer.

**“An adolescent’s perception of his/her own responsibility towards chronic illness” was positively associated with a willingness to transfer to adult care. Other independent variables, such as acceptance of the disease, trust to current doctor and confidence in future doctor, were found to be non-significant. Also, there was no significant difference in the transition decision in different genders, age groups, chronic disease type or severity of disease (Wong 2010).**

Patients who were more knowledgeable about their heart condition were more likely to respond to providers’ questions themselves and had more understanding of the implications of transition to adult care. Patients who were able to explain their diagnosis in both lay and medical terms appeared to be more confident. They communicated directly with providers instead of using their parents as a proxy and were self-assured in their ability to take care of themselves (Clarizia 2009).

The relationship with a clinician, clinician’s attitude to transition and the delivery of age appropriate care were found to be important factors (Coyne 2012).

Needs:

Services should be flexible and focus on young people’s needs (Machado 2010).

Jones 2008 identified the following adolescent needs during transition: a transition programme that caters for the individual and their cognitive level; recognition of adolescents’ increasing need for autonomy; recognition of the need for psychological support; the on-going battle for control; inclusion and support of the patient’s family and developmentally appropriate care.

The developmental level of the patient needs to be acknowledged and this should be used to individualise the amount of autonomy granted to the patient. Providers assumed that patients were ready to take responsibility for their own care; in fact some preferred not to be treated as adults immediately. Some mentioned a programme for young adults (Wiener 2011). **Gilliam 2009 reported that a transition plan needs to be tailored to the individual, incorporating a holistic approach that takes into account the medical and psychosocial needs of the individual. Special consideration should be given to adolescents with cognitive or developmental delays. Pregnant adolescent females were found to experience a smoother and more successful transition to adult care.**

**It is important to establish a transition policy and programme that is explicit and formalised, and which utilises timelines that are tied to individual patients’ developmental stages rather than a rigid schedule (Michaelis 2009).**

Preparation for transition should include an assessment of vocational needs, educational plans, encouragement of work experiences and a vision for future employment, along with life skills training (Wiener 2011).

### ***Confidence/responsibility/self-management***

Young people need flexible and age-appropriate support to develop the necessary skills to undertake a lead in decision-making about the management of their care (Brooks 2009). Education about the chronic condition and self-management is needed (Betz 2004, Pai 2011, Jones 2008), as is encouraging self-management tasks and building self-confidence (Jalkut 2009). **Planned learning activities during transition should be given to enhance the adolescent's sense of autonomy, personal responsibility and independence (Gilliam 2009).** Key issues to address are the adolescent's understanding of his/her disease, current treatments, long-term complications and the impact of healthy and unhealthy behaviours (Collins 2012). **Improving youths' emotional readiness and skills for adult medical care, e.g. life skills workshops provided in clinics, is also needed (Michaelis 2009).**

Where appropriate youth should be involved in the planning of their future health care (De Beaufort 2010).

To ease transition some participants wished they had been given more responsibility while still in paediatric care, where they could make mistakes, but also learn to build the necessary competencies for self-management of care (Wiener 2011).

In order to foster independence different consulting patterns are needed respecting the adolescents' need for confidentiality and privacy. Adolescents should be seen alone, with the parent coming in at the end for a summary (Jones 2008, Clarizia 2009). Consultations should be longer than for paediatric or adult clinics.

Parents of children who were generally confident and knowledgeable about their child's diagnosis tended to encourage their child's independence by letting them see providers alone and encouraged them to take an active role in their care. A patient who is able to establish a relationship with his/her physician in the paediatric setting will have more confidence to do the same with a new adult provider; both the paediatric physician and the patient need to strive for this (Clarizia 2009).

Providers should take care to address patients' limited autonomy by working with them to take control of their healthcare and find ways to help them to manage the stigma they face daily (Vijayan 2009).

### ***Trust/fear/anxiety***

Young people need reassurance there will be no interruption of care and HCPs need to recognise young peoples' lack of trust/fear/anxiety relating to acquiring a new adult provider. Establishing trusting relationships between all involved is important (Jalkut 2009).

Preparation of an individual portfolio of information, developed in consultation with the patient and family, would reassure adolescents that the new clinical team have sufficient knowledge on which to base decisions and reduce the need for duplication of investigations and queries (Jones 2008).

There was a perceived change in stigma upon transitioning to adult care. The adult care setting typically has a more diverse client base and newly transitioning young adults would benefit from being prepared for coming into contact with people whose age, sexual

orientation, mode of transmission and severity of illness may be different from their own (Wiener 2011).

### ***Relationships***

**There needs to be closer collaboration of paediatric and adult clinic staff. It is important to establish strong interpersonal relationships with clinic staff and strategies for maintaining mutually beneficial clinic-patient relationships even after youths leave paediatric care, e.g. keep former patients involved by making them members of the clinic's community advisory board and enlisting them as mentors to younger patients (Michaelis 2009).** Having a coordinated approach where communication between paediatric and adult providers takes place prior to, and if clinically indicated, after transition, can reduce the sense of loss and feeling of abandonment. Having an individual maintain contact for several months after leaving the paediatric programme, if feasible, may reduce the anxiety and sense of loss (Wiener 2011).

Paediatric HIV care providers may need to be aware of their own reluctance to let go and also to address the issues of transition at earlier ages, once they acknowledge the sexual precocity of many adolescents (Vijayan 2009).

Relationship with clinician, clinician's attitude to transition and the delivery of age appropriate care are all important factors (Coyne 2012).

### ***Timing***

Timing is important and the transition process needs to start early and progress slowly, giving the adolescent the opportunity to develop the skills of self-management in preparation for the changes ahead. Timing should be flexible, rather than dependent on a specific age, ranging from mid-teens to early adulthood (Jones 2008, Pai 2011). Timing should be based on "an ideal age" for transfer, personal choice, level of maturity and the physician's decision (Betz 2004).

**The following factors need to be considered: the application of adolescent development theory; consideration of developmental age together with chronological age; early initiation of transition planning (ages 14 to 16) or when admitted to the adolescent care clinic and a gradual transition process. The six clinics that have a structured transition programme include introductions or gradual exposure of the adolescent to their adult provider and a tour of the potential adult clinics during the transition process. Continued contact between adolescents and their case manager during the first year after transfer to adult clinic was considered essential (Gilliam 2009).**

**During the year prior to attending the transition clinic more intensive preparations for adult care need to begin, including orientation visits to the adult clinics accompanied by a staff member from the paediatric clinic (Michaelis 2009, De Beaufort 2010).**

**Transition to adult care typically occurred shortly before a patient reached 25 years. Clinics found young people were unprepared for adult care at an earlier age (Michaelis 2009).** The ideal time for transition into the adult service (for young people with T1DM) was late in the teenage years or early in the twenties (Fleming 2001).

Fleming 2001 noted transition must be carefully managed so that the adolescent does not need to make an abrupt adaptation in their move from a supportive environment to one where they are expected to be independent. The timing of transfer should take into account an adolescent's physical development and emotional maturity and needs to occur at a time of relative stability in their health and be coordinated with other life transitions. There is a need for collaboration between paediatric and adult health care services, which will assist the structured care of adolescents.

### ***Service delivery***

It is important to conduct early joint clinics and adopt a multidisciplinary approach to transition (De Beaufort 2010).

There needs to be provision for access to interdisciplinary services, specifically mental health and case management. Adult providers do not address all patients' needs, specifically concerns about sexual activity, pregnancy and disclosure (Wiener 2011).

The following factors need to be considered: access to healthcare specialists and comprehensive services; improvements to logistics of health services such as appointment times, waiting areas and parking and attributes of care providers (Betz 2004).

Comprehensive services need to be provided including primary care, pharmacy and dental services and psychosocial services such as case management, mental health and support groups (Jones 2008).

Paediatric providers need to continue to be involved directly in the adult-orientated setting by inviting adult providers to the paediatric setting or by specifically creating transitional clinics for adolescents. This may provide an effective bridge to transition (Vijayan 2009).

### ***Skills/education for healthcare professionals***

Continuing education and professional training for paediatric and adult providers caring for young people with LTCs is desirable (Jalkut 2009). There is a need for healthcare workers to possess effective interpersonal and communication skills (Binks 2007).

Paediatric hospitalists should be prepared to meet the needs of adolescent and young adult patients with special health care needs by becoming familiar with the components of the transition process (Collins 2012).

More emphasis needs to be placed on educating medical trainees regarding the assessment and treatment of people with disabilities (Young 2009).

Adult providers need to learn skills specific to the treatment of youth with HIV. Participants felt the inclusion of primary caregivers in decision-making and treatment planning was critical, especially directly following transition from paediatric care and particularly with youth with special developmental needs (Wiener 2011). Adult-orientated care providers need to be aware of the protected healthcare environment from which these children come from and may have to tailor their language and approach to interacting with patients who have been followed in a paediatric HIV clinic. They should be aware of the specific challenges regarding adolescents with HIV. In particular, stigma played a prominent role in both the challenges to

care and the barriers to transition; this is an aspect of the disease that may significantly impede access to health care (Vijayan 2009).

Almost a quarter of youth interviewed said adult providers seemed to have limited understanding of the psychosocial issues of this age group. They need to address the common concerns of young people, including sexuality, substance use and other health promoting and harming behaviours (Wiener 2011).

Care should be provided by culturally competent (Gilliam 2009, Jones 2008) and lesbian/gay/bisexual/transgender (LGBT) friendly staff (Jones 2008).

### ***Formal transition process***

**Creating a new transition policy and programming that is explicit and formalised (Betz 2004, Machado 2010, De Beaufort 2010) and which utilises timelines that are tied to individual patients' developmental stages rather than a rigid schedule is recommended (Michaelis 2009).** Flexible timing, care coordination, transition clinic visits and interested adult-centred health care providers are all factors that need to be considered. There was limited empirical evidence, however, to support the impact of these elements (Binks 2007).

The delegation of explicit responsibilities and a clear definition of roles for each participant (including parents) are needed (Clarizia 2009). Large paediatric services should develop a "transition roadmap" detailing how and where the process occurs in each speciality (Machado 2010).

Monitoring of the effects of the transition process on drop-out rates and complications is needed; more than one method to promote successful transition should be used (De Beaufort 2010).

GPs and dieticians should form a part of the transition process and an email forum for young people to make contact and share information and experiences should be created (Irvine 2010).

More formal transition programmes are required in facilities with a large contingent of adolescents being transferred to adult-oriented services (Machado 2010). A new provider should be introduced to the adolescent at the start of the transition process. A flexible approach is needed as the adolescent adjusts to the new adult clinic environment (Jones 2008).

### ***Coordination***

Assistance coordinating the transition process, including help in enrolling in mental health support, locating an adult provider, plus assistance with the transfer of information between providers, help with paperwork and insurance, and assisting young people in getting to appointments is needed (Valenzuela 2011, Wiener 2011).

**Cross-clinic coordination enhancing collaboration between paediatric and adult clinics is needed (Michaelis 2009).**

Continuity of care is essential and requires full preparation on the part of the patient and family, but also the adult team should be receptive to the needs of young adults. A multidisciplinary approach to transition encourages continuity and coordination between services (Jones 2008). Professionals felt it was very important to involve general practice, community paediatricians and community therapists in transition care planning (Brooks 2009, Betz 2004). Adult services need to incorporate family dynamics and educational issues in the care of young people during and after transition (Brooks 2009).

Adolescents expressed their desire for a well-known individual (e.g. case manager from paediatric clinic; paediatric nurse practitioner) to see them through this transition period (Jones 2008, Coyne 2012, Jalkut 2009). Other studies also identified the need for a transition coordinator or 'champion' (Pai 2011, Brooks 2009). One study suggested that one person each from the paediatric and adult-oriented teams should be in charge of managing the transition (Machado 2010).

Successful transition programmes also included orientation tours and information provision (Coyne 2012), patient education, identification of a capable adult physician, health care planning focused on access to health insurance, development of self-management skills and flexible timing of the transition process (Pai 2011).

### ***Evaluation***

An evaluation of how successful transition is (De Beaufort 2010) and **the monitoring and evaluation of patient outcomes after transition is needed (Michaelis 2009).**

There needs to be a greater use of assessment tools and consistent and comparable measures to assist nurses in assessing patients in transition (Jones 2008).

### **Review question 3: What are the key issues for young people with long-term conditions and professionals involved in the transition process?**

Eight studies contained information relevant to review question 3: four systematic reviews (Binks 2007, Lugasi 2011, Nakhla 2008, While 2004), and four primary studies (Clarizia 2009, Valenzuela 2011, Wiener 2011, Young 2009).

*Table 4: Long-term conditions covered in review question 3*

Diabetes	2 studies: Nakhla 2008, While 2004
Unspecified LTCs	1 study: Lugasi 2011
HIV/ AIDS	2 studies: Valenzuela 2011, Wiener 2011
Congenital heart disease	2 studies: While 2004, Clarizia 2009
Cerebral palsy/spina bifida/ acquired brain injuries of childhood	1 study: Young 2009
Cystic fibrosis	1 study: While 2004
Learning disability	1 study: While 2004
Muscular dystrophy	1 study: While 2004

None of the included studies were of high validity or relevance. All of the included studies for review question three were of low to moderate validity.

#### ***Time constraints***

Time constraints were cited by young people as the main reason for lack of attendance at adult clinics (Nakhla 2008) and young people felt they should have more flexible hours, more time with providers in the adult service (Valenzuela 2008) and shorter waiting times for appointments (Nakhla 2008, Valenzuela 2011); it would also be helpful to have clinics in the evenings.

#### ***Attachment/abandonment***

Nakhla 2008 noted that young people felt a sense of abandonment by the paediatric team. For a smoother process they would prefer longer initial meetings with the adult diabetes team or visits with the adult team prior to being transferred to adult care. Young peoples' "ideal" diabetes centre should not be in a hospital setting and staff should be approachable and understand the issues of young people.

Several studies (Lugasi 2010, Young 2009, Valenzuela 2011) noted attachment issues to current health care providers and loss of strong and long-term relationships with providers with historical knowledge of their condition and clinical expertise after transition.

Strong feelings were particularly evident among participants who had disclosed their status with only a few of their family and friends (Valenzuela 2011).

Several participants indicated that they developed trust or faith in the adolescent team members over time and some continued to communicate with adolescent team members about disease-related concerns as well as life events and stressors (Valenzuela 2011).

### ***Confusion***

Some studies (Lugasi 2010, Young 2009, Valenzuela 2011, Binks 2007) noted a lack of knowledge and not knowing what to expect amongst participants. Patients and caregivers felt unprepared for their roles in the next health care setting (Binks 2007, Valenzuela 2011). After transition a lack of knowledge regarding self-management of their condition (Binks 2007) and the transition process (Young 2009), continuity, coordination between paediatric and adult services and information before transition, as well as a decline in attendance at clinic after transfer to adult services, was noted.

Binks 2007 found that limited access to health care practitioners for guidance after transition was a consistent concern across qualitative studies.

Valenzuela 2011 described anxiety and specific worries during the transition process. Participants indicated that the change was overwhelming. Worries included concerns about privacy and health status during transition.

### ***Lack of trust***

Lugasi 2010 noted concerns about quality of care in adult-centred care and not trusting adult providers to transfer medical records.

### ***Environment***

Lugasi 2010 noted patients reported not liking the environment and fears for their future seeing older and sicker patients. Adult care providers spoke more bluntly about their disease, lifestyle and treatment. They were described as less paternal and less flexible (Valenzuela 2011)

Young 2009 stated young people expressed concerns following transition as they found not only the access to care a challenge, but were also concerned about the type of care available. Participants also experienced adult care as marking a change in provider expectations and interactions. Many felt they were expected to be more responsible with making their appointments, arriving on time and making medical decisions, compared with when they were in adolescent care (Valenzuela 2011). In addition, young people had concerns relating to health care experiences in hospitals and emergency rooms (Young 2009).

Binks 2007 found that young people and professionals had a number of challenges in relation to the transition environment/service provided:

- A lack of multidisciplinary, comprehensive health services for adults with a chronic illness.
- A dearth of adult providers with interest in chronic illnesses of childhood.
- A lack of specialised training in the proper care of adults with CP and SB.
- Many adults with CP and SB continued to attempt to access paediatric health care services despite their age and changing needs.



- Others struggled to connect to appropriate adult-centred health care resources and the remainder stopped seeking medical attention either out of frustration or rebellion.

There is a need for on-going care because of on-going health issues, coupled with the development of new health issues in adulthood.

Valenzuela 2011 found in addition that young people's descriptions of adult care centred on differences in both the health care setting and the health care system. Young adults described increased concerns related to dealing more independently with insurance requirements. Many of the participants interviewed felt that as adults they were making healthier choices and/or had a more positive attitude about their health than when they were younger. Priorities for adult care differed. Some participants cared most about clinic location, while others were more concerned about privacy issues. Some participants wanted to attend a clinic providing childcare or care to both mothers and children with HIV. Participants also indicated that options for care providers were important.

### ***Patient choice and control***

Lugasi 2010 noted concerns over patient choice and control, a need for independence, having more control over decision making and young people feeling more responsible for the management of their condition.

Weiner 2011 found that many children born with HIV in the epidemic were not expected to survive to adulthood. Becoming academically or emotionally prepared for independent living or decision-making was not a priority for most primary caregivers or providers. With the advent of highly active anti-retroviral therapy (HAART), survival is now expected. The need to help these youths catch up academically and emotionally by reducing dependence on their families has become necessary for day-to-day living as well as transitioning care. This was expressed by participants who reported difficulty with relaying their own medical history, their expressed desire to keep their primary caregivers involved in their care and reluctance by either primary caregivers or paediatricians to give up control of their healthcare.

Clarizia 2009 found that the majority of patients had a basic knowledge of their heart conditions; only a third had a clear understanding of the implications and changes associated with their future transition to adult care. Nearly half expressed a desire for more information about their heart condition. Most parents were aware that their child would transition to adult care; nearly half had some concerns about transition and half felt their child was ready. Parents' involvement was extensive, with nearly all accompanying their child to medical appointments, two thirds staying with them for the entire visit and nearly half administering their medication. Most parents felt the institution was preparing their child for transition. Providers felt that currently children were not sufficiently prepared for transition. The majority thought children should start learning about transition between the ages of 13 and 16. Physicians were more involved in teaching about diagnosis and symptoms than nurses.

While (2004) found that 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 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.

Valenzuela 2011 reported that participants recommended young people receive more options and control around choosing a new provider. They emphasised that young people should be able to try different settings before settling on one.

### ***Preparation***

Lugasi 2010 noted recommendations for preparation towards transition. Patients most satisfied with their transition were those who had been transferred to an adult clinic within the same hospital and had met the providers before.

## 4. DISCUSSION

This section brings together a summary of the findings in relation to the models or components of models that are effective in ensuring a successful transition process, the main barriers and facilitating factors in implementing a successful transition programme and the key issues for young people with LTCs and professionals involved in the transition process.

The overarching theme from the findings is the requirement for a formal transition process for young people with LTCs. The suggestion is that transition needs to be planned and structured in such a way that young people experience a streamlined progression from paediatric to adult services. In order to achieve this, various models have been proposed that focus on service delivery and young people and/or providers. In this systematic review no single model was identified as the most effective, largely because studies tended to focus on the description of models rather than on how efficacious they were. Components of individual models that facilitate successful transition were, however, evident.

A structured transition process embedded in service delivery was advocated, with a written protocol detailing the steps involved, in order that organisations, HCPs, young people and their families were fully aware of what transition entailed. A key component of the process, and arguably the fundamental premise of transition, is self-management education, where young people receive education and skills training to equip them to take control and manage their condition. Many young people reported they lacked knowledge of their condition, did not understand the essential steps involved in managing an LTC and felt unprepared to carry out the tasks expected of them in the adult service. Therefore, contrary to what is happening at present, where self-management education is delivered on an ad-hoc basis, a common theme was the need for a specific education programme, appropriately planned and executed, and including an assessment of young people's self-management competencies, self-confidence and readiness to transition. Furthermore, it was proposed these aspects should be placed in the context of young people's lives and take account of their changing circumstances in relation to education, socialisation, housing and relationships.

Importantly, structured transition meant having designated transition clinics attended by both paediatric and adult HCPs, the aim being to provide an effective bridge between the two services. Close collaboration between paediatric and adult services was highlighted as a key factor in the continuity of care for young people with LTCs, as was the need for communication to be maintained at all times, before, during and after transition. In addition, a specific transition clinic was deemed to facilitate effective communication between the triad of paediatric HCPs, adult HCPs and young people and their families. Most importantly, it enabled young people to participate in discussions and decision-making in relation to their continuing care. Participation of young people and their families, along with the provision of choice and information, were emphasised as crucial factors in their on-going care regimen.

The appointment of a transition coordinator responsible for overseeing the management and administration of the transition process was regarded as an important role to be considered. Many young people reported they were reluctant to leave the safety and familiarity of paediatric care, namely the HCPs with whom they had established a long-standing relationship, to 'start over' and learn to trust an adult provider. Young people stated they experienced feelings of abandonment on leaving the paediatric team. A valuable aspect of

the transition coordinator's role was to maintain the link with young people and ensure their care remained personalised and consistent. Furthermore, in this role there is scope for the transition coordinator to liaise with the various health, social and education sectors, whose involvement in the transition process was regarded as invaluable. The major criticisms voiced by HCPs included poor inter- and intra- agency coordination, as well as the lack of communication between paediatric and adult HCPs and other adult care services in the community. Professionals felt it was very important to involve general practice, community paediatricians/nurses and community therapists in transition care planning. A transition coordinator, together with more extensive involvement from integrated primary care and social services throughout the transition process, are worth considering for the benefit of both young people and HCPs.

A recurrent theme was the need for the transition process to be centred on the young person. In practice the approach has to be gradual, flexible and developmentally appropriate. The model least likely to meet young peoples' needs sees transition as a single transfer event to an unfamiliar clinic, with completely new adult HCPs who have different views to their paediatric colleagues and the young people. A number of factors including: young peoples' age; maturity; cognitive ability; need in respect of the LTC; social/personal factors; psychological support and inclusion and support of the whole family, were highlighted as important. A developmentally appropriate transition process was put forward, tailored to the individuals' medical and psychosocial needs, starting as early as possible and progressing gradually using a holistic approach. This meant the transition plan had to be built around timelines that were tied to individual young people's developmental stages and individual circumstances rather than a rigid schedule devised to suit HCPs or the organisation. It was thought that timing should be flexible, rather than dependent on a specific age, with young people being given appropriate support at different stages to suit them, for example, access to counselling and/or psychological support when young people needed it and not when it was deemed appropriate to provide it. The need for a multidisciplinary approach to transition was regarded as essential with the provision of interdisciplinary services, including mental health and case management.

Information relating to the transition process was reported as a key requirement of young people and their families. The need for written and verbal information in the form of a 'roadmap' so families knew what to expect was a common theme. Young people and their families had concerns regarding the transition process itself, the lack of access to HCPs, including specialist/allied health professionals, and differences in care between paediatric and adult services. Therefore, appropriate information at the right time (too much information too soon may not be well understood) with the opportunity to revisit this, along with orientation tours of the adult clinic, had to be incorporated into a transition plan.

An emphasis was placed on training HCPs to treat young people with LTCs and the importance of effective interpersonal and communication skills. These elements were regarded as an integral part of undergraduate education and continuing professional development. Many HCPs highlighted unsatisfactory adult provider care, namely a lack of transition training and experience managing young people with LTCs. In addition, there was increasing recognition that HCPs needed to acknowledge young people's fears and anxieties regarding the transition process and acquiring a new adult provider. Young people required reassurance, which could be provided by the transition coordinator and through the joint preparation (involving the young person, their family and HCPs) of a young person's

portfolio, which detailed all the information necessary for the new adult provider. Documenting communication between the paediatric HCPs and young people, as well as between the paediatric and adult HCPs, was thought to be essential for ensuring continuity and quality of care.

Having the necessary resources in place to develop, maintain and evaluate transition programmes was regarded as essential and required a commitment on the part of individual organisations across all sectors. The benefits were thought to be increased support for HCPs, better continuity and quality of care for young people, a reduction in clinic drop-out rates and fewer disease-related complications.

## **Summary of key findings**

There are various transition models. No single model was identified as the most effective, but components of individual models that facilitate successful transition were evident.

Transition needs to be:

- Centred on young people and placed in the context of young people's lives and their changing circumstances.
- Age-appropriate and take into account young people's maturity, cognitive ability, need in respect of LTC, social/personal circumstances and psychological status, as well as inclusion of the whole family.
- A streamlined progression from paediatric to adult services as part of a planned and structured process embedded in service delivery.
- A multidisciplinary approach with involvement from professionals in general practice, community paediatricians/nurses, etc..

Transition needs to include:

- Self-management education as part of a specific education programme, incorporating an assessment of young people's self-management competencies, self-confidence and readiness to transition.
- Close collaboration between paediatric and adult services with designated transition clinics attended by paediatric and adult HCPs.
- A transition coordinator to maintain a link with young people and liaise with various health, education and social sectors.
- Participation of young people and their families with written and verbal communication between paediatric HCPs, adult HCPs and young people and their families.
- A consideration of young peoples' concerns regarding the transition process (feelings of abandonment on leaving the paediatric team and anxieties around acquiring a new adult provider), lack of access to HCPs in adult care and differences in care between paediatric and adult services.
- The joint preparation of a young person's portfolio that moves with the young person, to alleviate young people's fears and provide reassurance their new provider will have all the required information about their medical history, etc..
- Training of HCPs to treat young people with LTCs and to utilise effective interpersonal and communication skills.
- Resources to develop, maintain and evaluate transition programmes.

The benefits of a transition programme include increased support for HCPs, better continuity and quality of care for young people, a reduction in clinic drop-out rates and fewer disease-related complications.

#### Limitations of review

Scope: This systematic review was commissioned and designed to answer the review questions set out in the methods section:

- To identify and determine the effectiveness of different models or components of models of transition.
- To identify barriers and facilitating factors and to present the views of young people, their families and health care providers.

It did not aim to explore definitions of transition. Even though this review was commissioned by NHS Diabetes, it did not look exclusively at diabetes, but at all LTCs, although the findings are thought to be common to most LTCs. The review is focused on transitions in secondary health care due to the necessity to limit the scope to a manageable volume of literature. We acknowledge there is also substantial literature on transitions in education, social care and to “adulthood” in general, and that if one is to take a holistic approach to transition, these should also be considered.

Methodology: While the review followed accepted systematic review methodology (CRD 2009; Higgins & Green 2008), restrictions due to timescale and funding mean that some potentially relevant studies may not have been included in the review. The literature search went back only as far as 1990, so relevant systematic reviews published before this date may have been missed, although some earlier primary studies would have been reviewed in the included systematic reviews. A decision was made to only include English language papers, which could mean that some relevant studies published in other languages may have been missed. The decision to exclude primary studies which met the inclusion criteria, but had publication dates that fell within the search dates for the included systematic review, makes the assumption that all relevant primary studies published before these dates would have been included in the published systematic reviews. This may not be the case, as the systematic reviews may not have picked them up in the searches, or they may have been excluded as each review had different inclusion criteria. It is also the case that studies which give positive findings are much more likely to be published than studies which give negative findings, or show evidence of no effect, and so if we had only included published papers our review would also be subject to publication bias. As it is, we did include dissertations and conference abstracts, although we cannot be sure that our review is free from publication bias. Publication bias is compounded by language bias, where studies with strongly positive results tend to be published in English language journals, so by restricting inclusion to English language papers, there is a chance that our review findings are biased towards the positive.

#### Limitations of included studies

The included studies were on the whole of poor methodological quality. Systematic reviews scored a maximum of 6 out of 11 possible points, with most scoring 4 or less. Primary studies did a little better, with three (Gilliam, Michaelis and Wong) scoring 1 (high) for internal validity, and three (Michaelis, Valenzuela and Vijayan) scoring a (high) for relevance. However, four primary studies scored 3c (low validity and relevance).

The low validity of the included reviews and studies may be due to poor reporting rather than poor conduct of the research, perhaps as a result of word restrictions in journal articles. Indeed, two of the three primary studies which were judged to have high internal validity were dissertations and the lowest scoring review reports were published as abstracts only. It is possible, however, to provide more details of methodology in journal articles and to provide references to full reports, or links to material stored online, such as lists on included and excluded studies. The overall impression gained on assessing the validity of these 29 studies was the study authors were not aware of the importance of reporting methodological detail, which suggests that perhaps the studies were not methodologically sound in their conduct. This means that most of the review findings should be treated with caution, as they are not based on strong evidence.

## 5. CONCLUSIONS

This systematic review sought to provide an up-to-date overview of the evidence regarding transition services for young people with long term conditions (LTCs), focusing particularly on transition models or components of models that are effective in ensuring a successful transition process, the main barriers and facilitating factors and key issues for young people with LTCs and professionals involved in the transition process. The key factors underpinning a successful transition programme included: a structured well planned transition process embedded in service delivery; a written transition protocol or 'roadmap'; a multi-disciplinary approach with close collaboration and effective documented communication between paediatric and adult services and young people and their families. Designated transition clinics attended by both paediatric and adult HCPs were seen as essential and the appointment of a transition coordinator to oversee the process was seen as key. Most importantly, it was advocated the transition process should start as early as possible and be young person-centred, flexible and developmentally appropriate to take into account young people's age, maturity, cognitive ability, need in respect of their LTC, social/personal factors and psychological support. Young people need to feel thoroughly prepared for transition both emotionally and in terms of self-management skills, therefore, a continuous self-management education programme must be provided. There also needs to be sufficient support for young people post-transfer with adequate monitoring of patient outcomes following transition. Having the necessary resources in place to develop, maintain and evaluate transition programmes was seen as essential to their success. This requires a committed approach from individual organisations across all sectors and potentially, could benefit the service with better continuity and quality of care for young people, enhanced support for HCPs and fewer clinic drop-outs and disease related complications.

The findings of this systematic review should be treated with some caution as the methodological quality of the included studies was generally poor. The review was also limited to focusing on transitions in secondary health care, whereas complementary research on transitions in education, social care and to "adulthood" in general, should also be reviewed and considered, in order to ensure a holistic approach to transition.

In conclusion, this review has reported a number of facilitating components of models of transition and highlighted the barriers and key issues for young people during transition. In addition, it has suggested recommendations that can be used to inform more efficacious transition planning for young people with LTCs and their families. Taken as a whole, this systematic review of transition across all LTCs represents an important and timely document because of its relevance to the new NHS Improving Quality priorities, specifically the children and young people's transition to adulthood services improvement programme.



## 6. RECOMMENDATIONS

The following recommendations are based on the findings from the systematic review. They are important as an evidence base, in terms of the ways in which transition needs to change to improve the continuity and quality of care for young people with LTCs and their long-term outcomes.

### **Young people-centred**

Every transition programme needs to be built around timelines that are tied to individual young people's developmental stages and circumstances, rather than a rigid schedule devised to suit HCPs/ organisations. The process should start as early as possible and be flexible taking into account young people's age, maturity, cognitive ability, need in respect of the LTC, social/personal factors and psychological support.

### **A planned and structured process**

A transition programme should be embedded in service delivery with a written protocol/'roadmap' detailing the steps involved, so that organisations, HCPs, young people and their families are fully aware of what transition entails. The process needs to include designated transition clinics attended by both paediatric and adult HCPs and orientation tours of adult clinics. There needs to be provision for post-transition support and monitoring, as well as evaluation of young people's outcomes after transition.

### **Self-management education**

Transition needs to be based on a continuous education programme through which young people receive education and skills training to equip them to take control and manage their condition. This should include an assessment of young people's self-management competencies, self-confidence and emotional skills and readiness to transition.

### **A transition coordinator**

There is a need for a nominated individual to take on the role of transition coordinator. Such a person is responsible for overseeing the management and administration of the transition process and for maintaining a link with the young person, in order to ensure young people's care remains consistent. The transition coordinator can help to alleviate any fears and concerns that the young person has in relation to leaving paediatric care and moving to a new adult provider.

### **Multidisciplinary approach**

Transition needs to encompass inter- and intra- agency communication and coordination. Integrated primary care and social service involvement throughout the transition process is an important aspect of transition.

### **Collaboration and communication**

Close collaboration and documented communication between paediatric HCPs, adult HCPs and young people and their families is essential, before, during and after transition. The creation of a young person's portfolio is advocated to ensure the new adult provider has all the required information about a young person's medical/life history. Young people and their families need to be involved in the preparation of the portfolio, participate in discussions and be provided with choices and appropriate information, in order that they can make informed decisions about their on-going care regimen. Cross-clinic coordination is essential.

**Training of HCPs**

A greater emphasis needs to be placed on training HCPs to treat young people with LTCs and the importance of effective interpersonal and communication skills. These should form an integral part of undergraduate education and continuing professional development.

**Resources**

Individual organisations across all sectors need to be committed to providing the necessary resources for developing, maintaining and evaluating transition programmes, in order that young people with LTCs and their families derive the maximum benefit from their transition experience.

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## APPENDIX A SEARCH STRATEGY

### The following databases were searched in August 2012:

MEDLINE (1990 – 2012)

EMBASE (1990 – 2012)

PsychINFO (1990 – 2012)

The Campbell Library

The Cochrane Library

CINAHL (1990 – 2012)

Academic Search Complete (1990 – 2012)

ASSIA (1990-2012)

Web of Science- Social Science Citation Index (1990- 2012)

### Using the following search strategy:

#### Medline:

((MESH.EXACT("Cystic Fibrosis") OR MESH.EXACT("Kidney Diseases") OR MESH.EXACT("Asthma") OR MESH.EXACT("Urologic Diseases") OR MESH.EXACT("Female Urogenital Diseases") OR MESH.EXACT("Diabetes Insipidus, Nephrogenic") OR MESH.EXACT("Renal Insufficiency") OR MESH.EXACT("Renal Insufficiency, Chronic") OR MESH.EXACT("Long-Term Care") OR MESH.EXACT("Patient Care") OR MESH.EXACT("Diabetes Insipidus")) OR (MESH.EXACT("Palliative Care") OR MESH.EXACT("Epilepsy") OR MESH.EXACT("Nervous System Diseases") OR MESH.EXACT("Specialties, Surgical") OR MESH.EXACT("Cerebral Palsy") OR MESH.EXACT("Health Services") OR MESH.EXACT("Child Health Services") OR MESH.EXACT("Adolescent Health Services") OR MESH.EXACT("Attention Deficit and Disruptive Behavior Disorders") OR MESH.EXACT("Attention Deficit Disorder with Hyperactivity") OR MESH.EXACT("Transplantation") OR MESH.EXACT("Organ Transplantation"))))

AND (MESH.EXACT("Transition to Adult Care") OR MESH.EXACT("Continuity of Patient Care") OR MESH.EXACT("Patient Transfer"))

(diabet\* OR "long term condition\*" OR "long term care" OR asthma OR renal OR "cystic fibrosis" OR cardiology OR CVD OR "cardiovascular disease" OR "complex healthcare needs" OR "chronic neurological problems" OR "chronic disease" OR "chronic illness" OR "kidney failure" OR "kidney care" OR "kidney services" OR "kidney insufficiency " OR "kidney disease" OR "chronic condition\*" OR "patient care" OR "palliative care" OR epilep\* OR transplant OR "cerebral palsy" OR cancer OR oncolog\* OR "health services" OR "patient

care" OR "adult care" OR ADHD OR "attention deficit" OR hyperactiv\* OR "long term neurologic\*")

AND

(Transition\* OR (continuity NEAR/3 care) OR "cross-boundary" OR transfer) NEAR/20 (Child\* OR young OR adolescent OR teenage\* OR youth OR pediatric OR paediatric OR juvenile)

### **Cinahl Subject Headings:**

(MH "Cystic Fibrosis") OR (MH "Kidney Diseases") OR (MH "Kidney Failure, Chronic") OR (MH "Renal Insufficiency") OR (MH "Renal Insufficiency, Chronic") OR (MH "Asthma") OR (MH "Urologic Diseases") OR (MH "Male Urogenital Diseases") OR (MH "Female Urogenital Diseases") OR (MH "Diabetes Mellitus") OR (MH "Diabetes Mellitus, Type 1") OR (MH "Diabetes Mellitus, Type 2") OR (MH "Long Term Care") OR (MH "Patient Care") OR (MH "Palliative Care") OR (MH "Epilepsy") OR (MH "Nervous System Diseases") OR (MH "Specialties, Surgical") OR (MH "Cerebral Palsy") OR (MH "Health Services") OR (MH "Child Health Services") OR (MH "Adolescent Health Services") OR (MH "Attention Deficit Hyperactivity Disorder")

(MH "Transitional Programs") OR (MH "Continuity of Patient Care") OR (MH "Transfer, Discharge")

### **ASSIA Subject Headings:**

Searched for:((SU.EXACT("Diabetes mellitus") OR SU.EXACT("Nervous system disorders") OR SU.EXACT("Health services") OR SU.EXACT("Palliative care") OR SU.EXACT("Cystic fibrosis") OR SU.EXACT("Chronic kidney failure") OR SU.EXACT("Patient care") OR SU.EXACT("Cerebral palsy") OR SU.EXACT("Diabetes") OR SU.EXACT("Kidney diseases") OR SU.EXACT("Diabetes insipidus") OR SU.EXACT("Attention deficit hyperactivity disorder") OR SU.EXACT("Epilepsy") OR SU.EXACT("Asthma") OR SU.EXACT("Long term care") OR SU.EXACT("Kidney failure") OR SU.EXACT ("Transplants") AND (SU.EXACT("Transition programmes"))

### **Social Services Abstracts**

Searched for:((SU.EXACT("Diabetes") OR SU.EXACT("Attention Deficit Disorder") OR SU.EXACT.EXPLODE("Cerebral Palsy") OR SU.EXACT("Health Care Services") OR SU.EXACT.EXPLODE("Long Term Care") OR SU.EXACT("Palliative Care") OR SU.EXACT.EXPLODE("Epilepsy"))



## Ovid search strategy

### From Medline (updated from Embase)

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<input type="checkbox"/>	10 cerebral palsy/	14368
<input type="checkbox"/>	11 attention deficit disorder/	17546
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<input type="checkbox"/>	14 12 and 13	202
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<input type="checkbox"/>	29 27 and 28	2056
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<input type="checkbox"/>	33 kidney failure/ or kidney disease/	76369

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<input type="checkbox"/>	42 attention deficit disorder/	17546
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<input type="checkbox"/>	62 52 or 57 or 60 or 61	2086
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<input type="checkbox"/>	71 Specialties, Surgical/	1894
<input type="checkbox"/>	72 Transplants/	1770
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<input type="checkbox"/>	74 "Continuity of Patient Care"/ or Transition to Adult Care/	13011
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<input type="checkbox"/>	82 59 and 79	510
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## Embase search strategy

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<input type="checkbox"/>	25	13 and 24	11353
<input type="checkbox"/>	26	20 and 25	1223
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<input type="checkbox"/>	27	"chronic condition*" or asthma* or "patient care" or "palliative care" or epilep* or transplant or "cerebral palsy" or cancer or oncolog* or "health services" or "patient care" or "adult care" or ADHD or "attention deficit" or hyperactiv* or "long term neurologic*").mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]	2836280
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## APPENDIX B DATA EXTRACTION FORMS

### Long-term condition transition model review

#### Data extraction form for systematic reviews

Reviewer:	
Checked by:	
Agreed: (date)	
Bibliographic details:	
Relevant to review questions:	
<b>STUDY DESIGN:</b>	
Databases searched:	
Years searched:	
Languages included:	
<b>REVIEW QUESTIONS:</b>	
<b>INCLUSION CRITERIA</b>	
POPULATION <i>e.g. age, sex, health condition, country</i>	
INTERVENTION/ COMPARATORS	
OUTCOMES	



STUDY DESIGNS	
FINDINGS	
Limitations/weaknesses of review <i>As reported by authors</i>	
Any other comments	

## Long-term condition transition review

### Data extraction form for primary studies

Reviewer:	
Checked by:	
Agreed: (date)	
Bibliographic details:	
Country:	
Relevant to review questions:	
Study design:	
Method of data collection <i>e.g. 15 Semi structured interviews &amp; 2 focus groups</i>	
<b>INTERVENTION</b>	
Description of model/ intervention	
Theoretical model (if given)	
Condition <i>e.g. diabetes</i>	
Comparator?	
Setting	
Who delivered it?	
<b>POPULATION</b>	
Target recipients ( <i>who it was aimed at</i> ) <i>e.g. age, sex, health condition</i>	
Outcomes for individuals: <i>List outcomes, how each was measured (e.g. scale), who measured it and when it was measured.</i>	

Clinical/ health outcomes	
Service delivery, organisational outcomes.  <i>List outcomes</i>	
<i>Whose perspective?</i>  <i>List whose views, if any, are reported (e.g. patients, parents, caregivers)</i>	
Costs/economic matters  <i>State whether paper contains any economic info.</i>	
Key process issues - Barriers	
Key process issues – facilitating factors	
Key issues for young people	
Recommendations for successful transition	
Any negative impacts reported?  <i>Yes/ No</i>  <i>Individual/ organisational etc.</i>	
Limitations/weaknesses of study  <i>As reported by authors</i>	
Any other comments	

## APPENDIX C VALIDITY ASSESSMENT FORMS

### 1. Validity assessment form for Systematic reviews

Study ID:.....

Reviewer:.....

<p><b>1. Was an 'a priori' design provided?</b> The research question and inclusion criteria should be established before the conduct of the review.</p>	<p>Yes No Can't answer Not applicable</p>
<p><b>2. Was there duplicate study selection and data extraction?</b> There should be at least two independent data extractors and a consensus procedure for disagreements should be in place.</p>	<p>Yes No Can't answer Not applicable</p>
<p><b>3. Was a comprehensive literature search performed?</b> At least two electronic sources should be searched. The report must include years and databases used (e.g. Central, EMBASE, and MEDLINE). Key words and/or MESH terms must be stated and where feasible the search strategy should be provided. All searches should be supplemented by consulting current contents, reviews, textbooks, specialised registers, or experts in the particular field of study, and by reviewing the references in the studies found.</p>	<p>Yes No Can't answer Not applicable</p>
<p><b>4. Was the status of publication (i.e. grey literature) used as an inclusion criterion?</b> The authors should state that they searched for reports regardless of their publication type. The authors should state whether or not they excluded any reports (from the systematic review), based on their publication status, language etc.</p>	<p>Yes No Can't answer Not applicable</p>
<p><b>5. Was a list of studies (included and excluded) provided?</b> A list of included and excluded studies should be provided.</p>	<p>Yes No Can't answer Not applicable</p>
<p><b>6. Were the characteristics of the included studies provided?</b> In an aggregated form such as a table, data from the original studies should be provided on the participants, interventions and outcomes. The ranges of characteristics in all the studies analysed e.g. age, race, sex, relevant socioeconomic data, disease status, duration, severity, or other diseases should be reported.</p>	<p>Yes No Can't answer Not applicable</p>
<p><b>7. Was the scientific quality of the included studies assessed and documented?</b> 'A priori' methods of assessment should be provided (e.g., for effectiveness studies if the author(s) chose to include only randomised, double-blind, placebo controlled studies, or allocation concealment as inclusion criteria); for other types of studies alternative items will be relevant.</p>	<p>Yes No Can't answer Not applicable</p>
<p><b>8. Was the scientific quality of the included studies used appropriately in formulating conclusions?</b> The results of the methodological rigor and scientific quality should be considered in the analysis and the conclusions of the review, and explicitly stated in formulating recommendations.</p>	<p>Yes No Can't answer Not applicable</p>

<p><b>9. Were the methods used to combine the findings of studies appropriate?</b> For the pooled results, a test should be done to ensure the studies were combinable, to assess their homogeneity (i.e. Chi-squared test for homogeneity, I<sup>2</sup>). If heterogeneity exists a random effects model should be used and/or the clinical appropriateness of combining should be taken into consideration (i.e. is it sensible to combine?).</p>	<p>Yes No Can't answer Not applicable</p>
<p><b>10. Was the likelihood of publication bias assessed?</b> An assessment of publication bias should include a combination of graphical aids (e.g., funnel plot, other available tests) and/or statistical tests (e.g., Egger regression test).</p>	<p>Yes No Can't answer Not applicable</p>
<p><b>11. Was the conflict of interest stated?</b> Potential sources of support should be clearly acknowledged in both the systematic review and the included studies.</p>	<p>Yes No Can't answer Not applicable</p>

## 2. Quality assessment checklist for quantitative studies

Reviewer ID:

++ Criteria are all met; + some criteria are met; - criteria are not or poorly met; **NR** not reported; **NA** not applicable

<b>Study identification</b> (Include full citation details)		
<b>SECTION 1: POPULATION</b>		
<p><b>1.1 Is the source population or source area well-described?</b> Was the country, setting, location, population demographics etc. adequately described?</p>	<p>++ + - NR NA</p>	Comments
<p><b>1.2 Is the recruited population representative of the source population?</b> Was the eligible population representative of all patients? Were important groups under-represented? <b>Study participants:</b> Was the method of selection of participants well described? What % of selected individuals agreed to participate? Were there any sources of bias? Were the inclusion/exclusion criteria explicit and appropriate?</p>	<p>++ + - NR NA</p>	Comments
<b>Section 2: Method of allocation to intervention (and comparison)</b>		
<p><b>2.1 Allocation to intervention (or comparison). How was selection bias minimised?</b> Was allocation to intervention and comparison Randomised (++)? If not randomised, was significant confounding likely (-) or not (+)?</p>	<p>++ + - NR NA</p>	Comments
<p><b>2.2 Were interventions (and comparisons) well described and appropriate?</b></p>	<p>++ +</p>	Comments

Were intervention/s and comparison/s described in sufficient detail (i.e. enough for study to be replicated)? Were comparison/s appropriate (e.g. usual practice rather than no intervention)?	- NR NA	
<b>2.3 Was the allocation concealed?</b> Could the person(s) determining allocation of participants to intervention or comparison groups have influenced the allocation? <i>Adequate allocation concealment (++) would include centralised allocation or computerised allocation systems.</i>	++ + - NR NA	Comments
<b>2.4 Was the exposure to the intervention and comparison adequate?</b> Within the study population (i.e. prison) was the intervention implemented as planned or did some prisoners who should have received the intervention not receive it? If not, could this bias the results (e.g. was there systematic bias)?	++ + - NR NA	Comments
<b>2.5 Was contamination acceptably low?</b> Did any in the comparison group receive the intervention or vice versa? If so, was it sufficient to cause important bias? If a cross-over trial, was there a sufficient washout period between interventions?	++ + - NR NA	Comments
<b>2.6 Were other interventions similar in both groups?</b> Did either group receive additional interventions or have services provided in a different manner? Were the groups treated equally by researchers or other professionals? Was this sufficient to cause important bias?	++ + - NR NA	Comments
<b>2.7 Were all participants accounted for at study conclusion?</b> Were the numbers lost-to-follow-up acceptably low (i.e. typically <20%)? Did the proportion dropped differ by group?	++ + - NR NA	Comments
<b>SECTION 3: OUTCOMES</b>		
<b>3.1 Were outcome measures reliable?</b> Were outcome measures subjective or objective? How reliable were outcome measures (e.g. inter- or intra-rater reliability scores for scales)? Was there any indication that scales had been validated (e.g. validated against a gold standard measure or assessed for content validity)?	++ + - NR NA	Comments
<b>3.2 Were all important outcomes assessed?</b> Were all important benefits and harms assessed? Was it possible to determine the overall balance of benefits and harms of the intervention versus comparison?	++ + - NR NA	Comments

<p><b>3.3 Were there similar follow-up times in exposure and comparison groups?</b> Analyses can be adjusted to allow for differences in length of follow-up (e.g. using person-years).</p>	<p>++ + - NR NA</p>	<p>Comments</p>
<p><b>3.4 Was follow-up time meaningful?</b> Was follow-up long enough to assess long-term benefits/harms? Was it too long, e.g. participants lost to follow-up?</p>	<p>++ + - NR NA</p>	<p>Comments</p>
<p><b>SECTION 4: ANALYSES</b></p>		
<p><b>4.1 Were exposure and comparison groups similar at baseline? If not, were these adjusted?</b> Were there any differences between groups in important confounders at baseline? If so, were these adjusted for in the analyses?</p>	<p>++ + - NR NA</p>	<p>Comments</p>
<p><b>4.2 Was Intention to treat (ITT) analysis conducted?</b> Were all participants (including those that dropped out or did not fully complete the intervention course) analysed in the groups to which they were originally allocated?</p>	<p>++ + - NR NA</p>	<p>Comments</p>
<p><b>4.3 Was the study sufficiently powered to detect an intervention effect (if one exists)?</b> A power of 0.8 (i.e. it is likely to see an effect of a given size if one exists, 80% of the time) is the conventionally accepted standard. Is a power calculation presented? Is the sample size adequate?</p>	<p>++ + - NR NA</p>	<p>Comments</p>
<p><b>4.4 Were the estimates and precision of intervention effects given or calculable? Were they meaningful?</b> Were effect estimates (e.g. relative risks, absolute risks) given or possible to calculate? Were confidence intervals (CIs) and/or p-values for effect estimates given or possible to calculate?</p>	<p>++ + - NR NA</p>	<p>Comments</p>
<p><b>4.5 Were the analytical methods appropriate?</b> Were important differences in follow-up time and likely confounders adjusted for? Were subgroup analyses pre-specified?</p>	<p>++ + - NR NA</p>	<p>Comments</p>
<p><b>SECTION 5: SUMMARY</b></p>		
<p><b>5.1 Are the study results internally valid (i.e. unbiased)?</b> How well did the study minimise sources of bias (i.e. adjusting for potential confounders)? Were there significant flaws in the study design?</p>	<p>++ + - Can't tell (not enough details)</p>	<p>Comments</p>
<p><b>5.2 Are the findings generalisable to the source population (i.e. externally valid)?</b> Are there sufficient details given about the study to determine if the findings are generalisable to</p>	<p>++ + - Can't tell</p>	<p>Comments</p>

the source population? Consider: participants, interventions and comparisons, outcomes, resource and policy implications. Was sample size adequate?	(not enough details)	
<b>5.3 What weight would you assign to this study in terms of its contribution to this review?</b>  Consider: <ul style="list-style-type: none"> <li>• The match between the study aims and findings and the aims and purpose of the synthesis</li> <li>• Its conceptual depth/ explanatory power</li> </ul>	++ + - Can't tell (not enough details)	

### 3. Qualitative studies: criteria used for appraisal of study quality

Study ID:

Reviewer ID:

<b>1. Were steps taken to increase rigour in the sampling?</b>  Consider whether: <ul style="list-style-type: none"> <li>• The sampling strategy was appropriate to the questions posed in the study (e.g. was the strategy well-reasoned and justified?).</li> <li>• Attempts were made to obtain a diverse sample of the population in question (think about who might have been excluded; who may have had a different perspective to offer).</li> <li>• Characteristics of the sample critical to the understanding of the study context and findings were presented (i.e. do we know who the participants were in terms of, for example, basic socio-demographics, characteristics relevant to the context of the study etc.).</li> </ul>	Yes, a fairly thorough attempt was made (++)  Yes, a few steps were taken (+)  No, not at all (-)  Not reported/ can't tell  NA
<b>2. Were steps taken to increase rigour in the data collected?</b>  Consider whether: <ul style="list-style-type: none"> <li>• Data collection tools were piloted.</li> <li>• Data collection was comprehensive, flexible and/ or sensitive enough to provide a complete and/ or vivid and rich description of people's perspectives and experiences (e.g. did the researchers spend sufficient time at the site/ with participants? Did they keep 'following up'? Was more than one method of data collection used?).</li> <li>• Steps were taken to ensure that all participants were able and willing to contribute (e.g. processes for consent, language barriers, power relations between young people and parents/ healthcare providers/ researchers).</li> </ul>	Yes, a fairly thorough attempt was made (++)  Yes, several steps were taken (+)  No, not at all (-)  Not stated/ can't tell  NA
<b>3. Were steps taken to increase rigour in the analysis of the data?</b> Consider whether: <ul style="list-style-type: none"> <li>• Data analysis methods were systematic (e.g. was a method described/ can a method be discerned?).</li> <li>• Diversity in perspective was explored.</li> <li>• The analysis was balanced in the extent to which it was</li> </ul>	Yes, a fairly thorough attempt was made (++)  Yes, several steps were taken (+)



<p>guided by preconceptions or by the data.</p> <ul style="list-style-type: none"> <li>The analysis sought to rule out alternative explanations for findings (in qualitative research this could be done by, for example, searching for negative cases/ exceptions, feeding back preliminary results to participants, asking a colleague to review the data, or reflexivity).</li> </ul>	<p>No, not at all (-) Not stated/ can't tell NA</p>
<p><b>4. Were the findings of the study grounded in/supported by the data?</b> Consider whether:</p> <ul style="list-style-type: none"> <li>Enough data are presented to show how the authors arrived at their findings.</li> <li>The data presented for the interpretation/ support claims about patterns in data.</li> <li>The data presented illuminate/ illustrate the findings.</li> <li>Quotes are numbered or otherwise identified and the reader can see that they don't just come from one or two people.</li> </ul>	<p>Good grounding/ support (++) Fair grounding/ support (+) Limited grounding/ support (-)</p>
<p><b>5. Please rate the findings of the study in terms of their breadth and depth.</b></p> <p>Consider whether (NB it may be helpful to consider 'breadth' as the extent of description and 'depth' as the extent to which data has been transformed/ analysed):</p> <ul style="list-style-type: none"> <li>A range of issues are covered.</li> <li>The perspectives of participants are fully explored in terms of breadth (contrast of two or more perspectives) and depth (insight into a single perspective).</li> <li>Richness and complexity has been portrayed (e.g. variation explained; meanings illuminated).</li> <li>There has been theoretical/ conceptual development.</li> </ul>	<p>Good/ fair breadth and depth Good/ fair breadth but very little depth Good/ fair depth but very little breadth Limited breadth or depth</p>
<p><b>6. To what extent does the study privilege the perspectives and experiences of young people?</b> Consider:</p> <ul style="list-style-type: none"> <li>Whether there was a balance between open-ended and fixed response options.</li> <li>Whether young people were involved in designing the research.</li> <li>Whether there was a balance between the use of an a priori coding framework and induction in the analysis.</li> <li>The position of the researchers (did they consider it important to listen to the perspectives of young people?).</li> <li>Whether steps were taken to assure confidentiality and put young people at ease.</li> </ul>	<p>A lot To some extent Not at all</p>
<p><b>7. Overall, what weight would you assign to this study in terms of the reliability/ trustworthiness of its findings?</b></p> <p>Guidance: Think (mainly) about the answers you have given to questions 1 to 4 above.</p>	<p>High Medium Low</p>
<p><b>8. What weight would you assign to this study in terms of the usefulness of its findings for this review?</b></p> <p>Guidance: Think (mainly) about the answers you have given to questions 5 and 6 above and consider:</p>	<p>High Medium Low</p>

- |  |  |
|--|--|
| <ul style="list-style-type: none"><li>• The match between the study aims and findings and the aims and purpose of the synthesis;</li><li>• Its conceptual depth/ explanatory power</li></ul> |  |
|--|--|

## APPENDIX D LIST OF INCLUDED STUDIES

### SYSTEMATIC REVIEWS

BETZ, C. L. 2004. Transition of adolescents with special health care needs: review and analysis of the literature. Issues in Comprehensive Pediatric Nursing, 27, 179-241.

BINKS, J. A., BARDEN, W. S., BURKE, T. A. & YOUNG, N. L. 2007. What do we really know about the transition to adult-centered health care? A focus on cerebral palsy and spina bifida. Archives of Physical Medicine and Rehabilitation, 88, 1064-1073.

BROOKS, F., BUNN, F. & MORGAN, J. 2009. Transition for adolescents with long-term conditions: event to process. British Journal of Community Nursing, 14, 301-304.

COYNE, I. T., BREEN, M., DEMPSEY, O. & WHILE, A. 2012. A systematic review of the transition process for young people with cystic fibrosis. Journal of Cystic Fibrosis, 11, S139.

CROWLEY, R., WOLFE, I., LOCK, K. & MCKEE, M. 2011. Improving the transition between paediatric and adult healthcare: a systematic review. Archives of Disease in Childhood, 96, 548-553.

DILEK, Y., BERNA, F. E. & DILEK, K. 2011. Transition to adult for adolescent with chronic condition and strategies of nursing. Acta Paediatrica, International Journal of Paediatrics, 100, 131-132.

DOUG, M., ADI, Y., WILLIAMS, J., PAUL, M., KELLY, D., PETCHEY, R. & CARTER, Y. H. 2011. Transition to adult services for children and young people with palliative care needs: a systematic review. Archives of Disease in Childhood, 96, 78-84.

FLEMING, E., CARTER, B. & GILLIBRAND, W. 2002. The transition of adolescents with diabetes from the children's health care service into the adult health care service: a review of the literature. Journal of Clinical Nursing, 11, 560-567.

JALKUT, M. K. & ALLEN, P. J. 2009. Transition from pediatric to adult health care for adolescents with congenital heart disease: a review of the literature and clinical implications. Pediatric Nursing, 35, 381-387.

JONES, S. E. & HAMILTON, S. 2008. The missing link: paediatric to adult transition in diabetes services. British Journal of Nursing, 17, 842-847.

LUGASI, T., ACHILLE, M. & STEVENSON, M. 2011. Patients' Perspective on Factors That Facilitate Transition From Child-centered to Adult-centered Health Care: A Theory Integrated Metasummary of Quantitative and Qualitative Studies. Journal of Adolescent Health, 48, 429-440.

MACHADO, D. M., SUCCI, R. C. & TURATO, E. R. 2010. Transitioning adolescents living with HIV/AIDS to adult-oriented health care: An emerging challenge. Jornal de Pediatria, 86, 465-472.

NAKHLA, M., DANEMAN, D., FRANK, M. & GUTTMANN, A. 2008. Translating transition: A critical review of the diabetes literature. Journal of Pediatric Endocrinology and Metabolism, 21, 507-516.

PAI, A. L. H. & OSTENDORF, H. M. 2011. Treatment Adherence in Adolescents and Young Adults Affected by Chronic Illness During the Health Care Transition From Pediatric to Adult Health Care: A Literature Review. Children's Health Care, 40, 16-33.

WATSON, R., PARR, J. R., JOYCE, C., MAY, C. & LE COUTEUR, A. S. 2011. Models of transitional care for young people with complex health needs: a scoping review. Child: Care, Health and Development, 37, 780-791.

WHILE, A., FORBES, A., R. Ullman, S. Lewis, L. Mathes and P. Griffiths., 2004. Good practices that address continuity during transition from child to adult care: synthesis of the evidence. Child: Care, Health and Development, 30, 439-452.

## PRIMARY STUDIES

BETZ, C. L., SMITH, K. & MACIAS, K. 2010. Testing the transition preparation training program: a randomized controlled trial. International Journal of Child and Adolescent Health, 3, 595-607.

CADARIO, F., PRODAM, F., BELLONE, S., BINOTTI, M., TRADA, M., ALLOCHIS, G., BALDELLI, R., ESPOSITO, S., BONA, G. & AIMARETTI, G. 2009. Transition process of patients with type 1 diabetes (T1DM) from paediatric to the adult health care service: A hospital-based approach. Clinical Endocrinology, 71, 346-350.

CLARIZIA, N. A., CHAHAL, N., MANLHIOT, C., KILBURN, J., REDINGTON, A. N. & MCCRINDLE, B. W. 2009. Transition to adult health care for adolescents and young adults with congenital heart disease: perspectives of the patient, parent and health care provider. The Canadian Journal of Cardiology, 25, e317-322.

DE BEAUFORT, C., JAROSZ-CHOBOT, P., FRANK, M., DE BART, J. & DEJA, G. 2010. Transition from pediatric to adult diabetes care: smooth or slippery? Pediatric Diabetes, 11, 24-27.

FERNANDES, S. M., FISHMAN, L., O'SULLIVAN-OLIVEIRA, J., ZINIEL, S., MELVIN, P., KHAIRY, P., O'BRIEN, R., WEBSTER, R. A., LANDZBERG, M. J. & SAWICKI, G. S. 2010. Current practices for the transition and transfer of patients with a wide spectrum of pediatric-onset chronic diseases: results of a clinician survey at a free-standing pediatric hospital. International Journal of Child and Adolescent Health, 3, 507-515.

GILLIAM, P. 2009. Transitional care for adolescents with HIV: characteristics and current practices of the Adolescent Trials Network systems of care. Ph.D., University of South Florida.

IRVINE, T., SRINIVASAN, R., CASSON, D. H., AUTH, M., DALZELL, A. M., CROOK, K., LEIPER, K., RHODES, J., GREEG, A. & KNEEBONE, A. 2010. Assessing the value of a pre-transfer meeting in IBD transition services. Gastrointestinal Nursing, 8, 19.

MICHAELIS, A. P. 2009. Helping young adults succeed in a world where 'you can't': Transitions to healthy adulthood for HIV-positive youths in Baltimore, Maryland. 70, ProQuest Information & Learning.

VALENZUELA, J. M., BUCHANAN, C. L., RADCLIFFE, J., AMBROSE, C., HAWKINS, L. A., TANNEY, M. & RUDY, B. J. 2011. Transition to Adult Services among Behaviorally Infected Adolescents with HIV--A Qualitative Study. Journal of Pediatric Psychology, 36, 134-140.

VIJAYAN, T., BENIN, A. L., WAGNER, K., ROMANO, S. & ANDIMAN, W. A. 2009. We never thought this would happen: transitioning care of adolescents with perinatally acquired HIV infection from pediatrics to internal medicine. AIDS Care, 21, 1222-1229.

WIENER, L. S., KOHRT, B.-A., BATTLES, H. B. & PAO, M. 2011. The HIV experience: youth identified barriers for transitioning from pediatric to adult care. Journal of Pediatric Psychology, 36, 141-54.

WONG, L., CHAN, F. W. K., WONG, F. Y. Y., WONG, E. L. Y., HUEN, K. F., YEOH, E. K. & FOK, T. F. 2010. Transition Care for Adolescents and Families With Chronic Illnesses. Journal of Adolescent Health, 47, 540-546.

YOUNG, N. L., BARDEN, W. S., MILLS, W. A., BURKE, T. A., LAW, M. & BOYDELL, K. 2009. Transition to adult-oriented health care: perspectives of youth and adults with complex physical disabilities. Physical and Occupational Therapy in Pediatrics, 29, 345-361.

## APPENDIX E LIST OF EXCLUDED STUDIES

### EXCLUDED AT SCREENING STAGE

#### Reason for exclusion: Not research

ANON 2010. New NDEP resource helps with transition from pediatric to adult care. Diabetes Dateline, 12-12.

ANDIMAN, W. A. 2011. Transition from pediatric to adult healthcare services for young adults with chronic illnesses: the special case of human immunodeficiency virus infection. Journal of Pediatrics, 159(5), 714-719.

BAILEY, S., O'CONNELL, B. & PEARCE, J. 2003. The transition from paediatric to adult health care services for young adults with a disability: an ethical perspective. Australian health review : a publication of the Australian Hospital Association, 26, 64-69.

BASHORE, L. M. 2011. Young Adults with Risk Factors for Chronic Disease: Transition Needs for Survivors of Childhood Cancer. Critical Care Nursing Clinics of North America, 23, 311-322.

BELL, L. E. & SAWYER, S. M. 2010. Transition of care to adult services for pediatric solid-organ transplant recipients. Pediatric Clinics of North America, 57, 593.

BELL, L. E., FERRIS, M. E., FENTON, N. & HOOPER, S. R. 2011. Health Care Transition for Adolescents With CKD-The Journey From Pediatric to Adult Care. Advances in Chronic Kidney Disease, 18, 384-390.

BERG, S. K. & HERTZ, P. G. 2007. Outpatient nursing clinic for congenital heart disease patients: Copenhagen Transition Program. Journal of Cardiovascular Nursing, 22, 488-492.

BERKOWITZ, S. 2009. Transitioning adolescents to adult care: putting theory into practice. Minnesota medicine, 92, 42-44.

BESKINE, D. & OWEN, P. 2008. Review of transitional care for young people with diabetes. Journal of Diabetes Nursing, 12, 4p.

BJORNSEN, K. D. 2004. Health care transition in congenital heart disease: the providers' view point. Nursing Clinics of North America, 39, 715-726.

BOWES, G., SINNEMA, G., SURIS, J.-C. & BUHLMANN, U. 1995. Transition Health Services for Youth with Disabilities: A Global Perspective. Journal of Adolescent Health, 17, 23-31.

BREAKEY, V. R., BLANCHETTE, V. S. & BOLTON-MAGGS, P. H. B. 2010. Towards comprehensive care in transition for young people with haemophilia V. R. BREAKEY et al. TRANSITION FOR HAEMOPHILIA. Haemophilia, 16, 848-857.

CAMFIELD, P. & CAMFIELD, C. 2011. Transition to adult care for children with chronic neurological disorders. Annals of Neurology, 69, 437-444.

CHAMPION, E. A., CONNELLY, M. & DELLON, E. P. 2011. Transition of patients with cystic fibrosis from pediatric to adult care: Development of a transition program. Pediatric Pulmonology, 46, 381.

CALLAHAN, S. T., FEINSTEIN, R. & KEENAN, P. 2001. Transition from pediatric to adult-oriented health care: a challenge for patients with chronic disease. Current Opinion in Pediatrics, 13, 310-316.

CHIARAVALLI, S., FRANZETTI, I., BIANCHI, G., SAPORITI, A., COSTANTINI, C. & SALVATONI, A. 2009. The transfer of the young diabetic from paediatric to adult diabetes service: The role of "caronte". Pediatric Diabetes, 10, 72.

- CHISANGA, E. 2009. Applying specialist nurse skills to improve epilepsy adolescent transition services. British Journal of Neuroscience Nursing, 5, 274-277.
- COLEMAN, R. & MOORE, S. 2006. Future considerations in the transition of paediatric neurodevelopmental patients to adult services. Australasian Journal of Neuroscience, 18, 15-20.
- CONWAY, S. P. 1998. Transition from paediatric to adult-orientated care for adolescents with cystic fibrosis. Disability and Rehabilitation, 20, 209-216.
- COOKE, E. 2007. Transitional care for young people with diabetes: policy and practice. Paediatric Nursing, 19, 19-22.
- COURT, J. M. 1991. Outpatient-based transition services for youth. Pediatrician, 18, 150-6.
- COWLARD, J. 2003. Cystic fibrosis: transition from paediatric to adult care. Nursing Standard, 18, 39-41.
- David. T.J. 2001. Transition from the paediatric to the adult service. Journal of the Royal Society of Medicine, 94 (8), 373- 374
- DEGNAN, A., GRIMES, J. L., HOHNEKE, A., JONES, L., NAU, A. & WARADY, B. 2012. Transition: Navigating the journey from pediatric to adult care. Peritoneal Dialysis International, 32, S24.
- DOULTON, D. M. 2010. From cradle to commencement: transitioning pediatric sickle cell disease patients to adult providers. Journal of Pediatric Oncology Nursing, 27, 119-123.
- DOWSHEN, N. & D'ANGELO, L. 2011. Health Care Transition for Youth Living With HIV/AIDS. Pediatrics, 128, 762-771.
- ELLINGFORD, C. (?). Refocusing transition clinics, Paediatric Nursing, 18 (6), 37.
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## APPENDIX F DATA EXTRACTION FORMS FOR INCLUDED STUDIES

### Systematic reviews

<b>Betz CL. Transition of adolescents with special health care needs: review and analysis of the literature. Issues in Comprehensive Pediatric Nursing 2004, 27: 179-241</b>	
Relevant to review questions: 1, 2, 3	
<b>STUDY DESIGN:</b>	
Databases searched:	MEDLINE, CINAHL
Years searched:	1982 - 2003
Languages included:	English only
<b>REVIEW QUESTIONS:</b>	Not stated. Aims of the review are: <ul style="list-style-type: none"> <li>1. To evaluate the methodological elements and summarise findings of study themes, transfer criteria, transition barriers and transition service recommendations.</li> <li>2. To identify the gaps and limitations of the research and the current knowledge available to provide recommendations for future research and suggested clinical implications.</li> </ul>
<b>INCLUSION CRITERIA</b>	
POPULATION <i>e.g. age, sex, health condition, country</i>	No inclusion criteria stated. Presumably adolescents with special health care needs.
INTERVENTION/COMPARATORS	No inclusion criteria stated. Presumably transition services/ models/ programs/ planning.
OUTCOMES	No inclusion criteria stated.
STUDY DESIGNS	No inclusion criteria stated. Majority used descriptive or qualitative designs.
FINDINGS	<p>43 studies were included.</p> <p>Transition research is in early stages of development, with lack of theoretical frameworks, use of valid and reliable instruments and research designs lacking adequate controls.</p> <p>Included studies addressed five major themes: transition needs and experiences of youth and families; transition program outcomes; tool development and testing; national data on profile of transition programs; role of physician in providing transition services.</p> <p>Transfer criteria: age (most frequently cited ideal age = 16-22 years); physiological status of special health care need or disability; presence of other problems; administrative issues; physician decision; marriage; pregnancy; knowledge of condition.</p> <p>Transition barriers: provider care (time restriction; lack of transition training; limited transition educational materials and transition counsels for providers; providers' level of professional competence; discomfort in talking about personal topics such as sex and drugs; not practicing responsibility; difficulty accessing resources; difficulty communicating with adult providers); young adults (lack of communication between paediatric and adult physicians; lack of and</p>

	<p>difficulty communicating with providers; communication problems (not being included in discussions re. their care and providers' unrealistic expectations re. their ability to be self-reliant); preparation problems; blurring of roles between parents and providers); system barriers (lack of money; lack of clinical guidelines; lack of institutional support; limited transition resource information for distribution; barriers accessing community resources; negative systemic and societal attitudes); parental (unreliability as historians; resistance; excessive dependence; high risk histories; confusion re extent of responsibility and "letting go"); youth (age; maturity; wishes; resistance; knowledge of condition; psychosocial situation).</p> <p>Recommendations: "ideal age" for transfer; personal choice; level of maturity; physician decision; need for formalised process; access to healthcare specialists and comprehensive services; improvements to logistics of health services such as appointment times, waiting areas and parking; attributes of care providers; education about chronic condition; self-management; integrated health and community transition services; counselling and psychosocial support; family support; advocacy; peer / social support.</p>
Limitations/weaknesses of review	None stated.
<i>As reported by authors</i>	
Any other comments	Lots of results but limited methods section, making it unclear what research questions or inclusion criteria were.

<b>Binks, J.A., Barden, W.S., Burke, T.A., Young, N.L. (2007). What Do We Really Know About the Transition to Adult-Centered Health Care? A Focus on Cerebral Palsy and Spina Bifida, Arch Phys Med Rehabil, 8, 1064- 1072.</b>	
Relevant to review questions: 2	
<b>STUDY DESIGN: SR</b>	
Databases searched:	Medline and CINAHL, author name search, reference list search
Years searched:	1990 to 2006
Languages included:	English language
<b>REVIEW QUESTIONS:</b>	<ol style="list-style-type: none"> <li>1) To identify barriers associated with the transition to adult-centred health care for Cerebral Palsy (CP) and Spina Bifida (SB) patients</li> <li>2) To outline key elements that should be included in the transition programme for these groups</li> <li>3) To review the empirical evidence related to the process and outcomes of that transition</li> </ol>
<b>INCLUSION CRITERIA</b>	
POPULATION <i>e.g. age, sex, health condition, country</i>	<ul style="list-style-type: none"> <li>• Young people with Spina Bifida or Cerebral Palsy transitioning to adult-centred healthcare</li> <li>• Young people with other conditions previously experienced in childhood but now common in adulthood</li> <li>• Studies focused on conditions other than CP or SB were included in this review only if they provided key information related to clinical transition that was considered relevant to CP or SB</li> </ul> <p>Most of the studies were conducted in the US, the bulk of the</p>

	remainder were done in the UK, Canada and Australia
INTERVENTION/ COMPARATORS	Transition programs
OUTCOMES	<ol style="list-style-type: none"> <li>1) Barriers to transition</li> <li>2) Key elements suggested for transition programmes</li> <li>3) Empirical Evidence Related to the Process and Outcomes of Transition</li> </ol>
STUDY DESIGNS	Not specified
FINDINGS	<p>Barriers to transition</p> <ol style="list-style-type: none"> <li>1) Child-centred health care providers: inability of health care professionals (e.g. paediatricians) to “let go” of their long standing relationships with patients and distrust of adult-centred health services.</li> <li>2) Youth: reluctant to leave the safety and familiarity of family-centred care</li> <li>3) Parents: Adult-centred services rarely engage with families in the same way as do child-centred services, parents may feel excluded from the decision making process.</li> <li>4) Adult-centred health care providers: May have limited training and experience with childhood chronic illnesses therefore have limited knowledge in caring for these young adults. May have limited resources to support the patients complex needs</li> </ol> <p>They identified five key elements that supported a positive transition to adult-centred health care: preparation, flexible timing, care coordination, transition clinic visits and interested adult-centred health care providers. There was limited empirical evidence to support the impact of these elements</p> <p>Empirical Evidence related to the Process and Outcomes of Transition</p> <ol style="list-style-type: none"> <li>1) Consistent methods from qualitative studies were that patients and caregivers were unprepared for their roles in the next health care settings, did not understand the essential steps in managing a chronic illness and had limited access to health care practitioners for guidance</li> <li>2) Overall limited evidence related to the process and outcomes of the transition to adult-centred health care for CP and SB patients</li> </ol> <p>Challenges:</p> <ul style="list-style-type: none"> <li>• Lack of multidisciplinary comprehensive health services for adults with a chronic illness</li> <li>• A dearth of adult providers with interest in chronic illnesses of childhood</li> <li>• Lack of specialised training in the proper care of adults with CP and SB.</li> <li>• Many adults with CP and SB continue to attempt to access paediatric health care services despite their age and changing needs</li> <li>• Others struggle to connect to appropriate adult-centred health care resources and the remainder stop seeking medical attention either out of frustration or rebellion</li> <li>• There is a need for on-going care because of on-going health issues coupled with the development of new health issues in</li> </ul>



	adulthood
Limitations/weaknesses of review <i>As reported by authors</i>	<ul style="list-style-type: none"> <li>• The primary limitation of this review is related to the source materials. The methods and data analysis sections of the source articles were often unclear (i.e. may not have specified the measurement properties of their data collection tools).</li> <li>• The different sampling strategies in the source articles limited ability to make comparisons across studies.</li> <li>• Difficult to apply standardised age groupings</li> <li>• Lack of detail on sample characteristics</li> </ul>
Any other comments	Not very well reported

<b>Brooks F, Bunn F, Morgan J. 2009. Transition for adolescents with long-term conditions: event to process. British Journal of Community Nursing 14: 301-304</b>	
Relevant to review questions: 1 & 2	
<b>STUDY DESIGN:</b>	
Databases searched:	? (See Wilson et al, 2009)
Years searched:	?
Languages included:	?
<b>REVIEW QUESTIONS:</b>	Paper maps the evidence relating to modelling of transition services for YP with LTCs in UK. Models and definitions of transition were reviewed and coordination of services, including role of PHC services were mapped.
<b>INCLUSION CRITERIA</b>	
POPULATION <i>e.g. age, sex, health condition, country</i>	Not specified.
INTERVENTION/ COMPARATORS	Other transition programmes.
OUTCOMES	Not specified.
STUDY DESIGNS	Not specified.
FINDINGS	<p>Four frameworks for good practice.</p> <p>Majority of lit. adopted following key principles/traits when considering transition: 'Participative, holistic, supportive, evolving, inclusive and collaborative'.</p> <p>Many papers adopted a specialty specific focus, without acknowledging learning from other specialties.</p> <p><b>Generic issues highlighted that contribute to effectiveness in transition:</b></p> <p>1. <b>YP centred process:</b> participation of YP is seen as key to the effective management of transition. They need flexible and age-appropriate support to develop the necessary skills to undertake a</p>

	<p>lead in decision-making about the management of their care.</p> <p>2. <b>Communication issues:</b> professionals need to acquire additional skills and knowledge in working with YP, including communication skills and understanding of the physiology of adolescence. Lack of staff development identified as barrier to successful transition. Communication between paediatric and adult services identified as central to achieving coordinated and planned transition process. Aspects of good communication include: key worker role within adult services; a full multi-agency assessment that provides structure for future communication as well as establishing systems for joint working and communication; systems need to ensure that all YPs notes are transferred.</p> <p>3. <b>Process and systems:</b> identified professional lead to ‘champion’ transition issues is needed. Effective transition is dependent on inter-agency coordination. Professionals felt it was very important to involve general practice, community paediatricians and community therapists in transition care planning. Role of PHC in monitoring transition for YP warrants further examination and modelling. Adult services need to incorporate family dynamics and educational issues in the care of YP during and after transition.</p> <p><b>Challenges and barriers:</b></p> <ol style="list-style-type: none"> <li>1. Poor inter- and intra- agency coordination from perspective of professionals</li> <li>2. The model least likely to meet YPs needs sees transition as a single transfer event to an unfamiliar clinic with completely new professionals whose views on condition management are different from the YPs previous practitioners.</li> <li>3. Lack of adequate resources in relation to transition planning</li> <li>4. Organisations failing to prioritise the process</li> <li>5. Gaps in levels of integration between sectors in the health care system also created barriers to transition process</li> <li>6. Rigid policies and protocols create inconsistencies in transition planning</li> </ol> <p>In <b>summary</b>, transition should be participative, supportive and flexible process. Should respond to individual needs of YP. Professionals should develop a renewed focus on relationships and communication with YP. Needs to be appropriate balance between risk and autonomy in planning transition. Transition programme should have individualised preparation period that includes age-appropriate information and visits to adult services.</p>
<p>Limitations/weaknesses of review <i>As reported by authors</i></p>	<p>Paucity of primary good quality research. Absence of good quality studies exploring adolescent experience of transition.</p>
<p>Any other comments</p>	<p>Linked to Wilson et al, 2009. Detailed methods of the review found here. Insufficient evidence from SR’s. Review was broadened re. transition and papers used from range of sources, e.g. descriptive reports, qualitative papers, case studies, policy docs and practice guides. This paper is the final in a series of 3 to review the evidence relating to the management of LTCs.</p>

<b>Coyne IT, Breen M, Dempsey O, While A. 2012. A systematic review of the transition process for young people with cystic fibrosis. Journal of Cystic Fibrosis, 11, S139</b>	
Relevant to review questions: 2, 3	
<b>STUDY DESIGN:</b>	
Databases searched:	CINAHL, EMBASE, PsychINFO, Pubmed
Years searched:	2001 - 2011
Languages included:	Not stated
<b>REVIEW QUESTIONS:</b>	How is the (transition) process experienced by young people with chronic illness? How does the transition process impact on young people's health and wellbeing? How is the transition process by all stakeholders?
<b>INCLUSION CRITERIA</b>	
POPULATION <i>e.g. age, sex, health condition, country</i>	No inclusion criteria stated -probably young people with chronic illness, especially but not exclusively cystic fibrosis
INTERVENTION/ COMPARATORS	No inclusion criteria stated - Transition process
OUTCOMES	No inclusion criteria stated. - Probably experiences of young people, impacts on health and wellbeing, and process issues
STUDY DESIGNS	No inclusion criteria stated. 7 qualitative and 10 quantitative studies on transition and cystic fibrosis were included.
FINDINGS	Despite transition, young adults continue to be dependent on their parents for support and assistance. Some parents resist the more marginal role they are expected to play in clinical consultations which can lead to tensions in the young person/ clinician/ parent triad.  Key facilitating factors: relationship with clinician, clinician's attitude to transition, delivery of age appropriate care.  Barriers: treatment burden, forgetting of treatments, lack of perceived benefit of treatments.  Successful transition programs included orientation tours, information provision and familiar face in adult clinics.
Limitations/weaknesses of review <i>As reported by authors</i>	None reported.
Any other comments	Abstract only – need to contact authors for full report (authors contacted, full report not yet available).

<b>Crowley, R., Wolfe, I., Lock, K., McKee, M. (2011) Improving the transition between paediatric and adult healthcare: a systematic review</b>	
Relevant to review questions: 1	
<b>STUDY DESIGN:</b>	

Databases searched:	MEDLINE, HMIC, PsychINFO and EMBASE
Years searched:	Does not state (looks like between 1992 and 2010 from refs)
Languages included:	Papers with an English title and abstract published in any language were considered
<b>REVIEW QUESTIONS:</b>	Not specified clearly  Paper systematically reviews the evidence of the effectiveness of transitional care interventions in improving health outcomes in a broad range of conditions (any chronic, physical or mental illness or disability), in order to identify key features on which clinicians can base future services and research.
<b>INCLUSION CRITERIA</b>	
POPULATION <i>e.g. age, sex, health condition, country</i>	A wide age range was included (11-25 years) Children have chronic disease, mental illness or disability Countries not specified  8 studies examined services for patients with diabetes mellitus, one for cystic fibrosis and one for organ transplant recipients
INTERVENTION/ COMPARATORS	Studies were included if <ul style="list-style-type: none"> <li>• They involved a health service intervention during the period of transition from paediatric to adult care</li> <li>• They evaluated changes in health outcomes following this transfer</li> <li>• Outcomes were compared either between an intervention and control group or pre-intervention and post-intervention in a single group</li> </ul>
OUTCOMES	Health outcomes: <ul style="list-style-type: none"> <li>• Disease specific biochemical indicators, such as HbA1c or creatinine, and/or health service use, such as percentage of missed follow-up appointments</li> <li>• More robust outcome measures included hospital admissions for diabetic ketoacidosis or prevalence of diabetic complications (nephropathy, retinopathy, hypoglycaemia)</li> <li>• None involved long-term follow up of morbidity or mortality</li> </ul>
STUDY DESIGNS	<ul style="list-style-type: none"> <li>• The studies varied in terms of overall study design, in the number and age range of participants, and the durations of intervention and follow-up.</li> <li>• Eight studies attempted comparison between an intervention group and controls</li> <li>• 2 studies did not use any comparison group, but measured outcomes of a single group of patients pre-transfer and post transfer</li> </ul>
FINDINGS	<ul style="list-style-type: none"> <li>• 10 studies met the inclusion criteria, 6 of which showed statistically significant improvements in outcomes.</li> <li>• All 6 interventions that resulted in significant improvements were in studies of patients with diabetes mellitus, with glycosylated haemoglobin level, acute and chronic complications, and rates of follow-up and screening used as outcome measures.</li> <li>• Descriptive analysis identified three broad categories of</li> </ul>

	intervention, directed at: the patient (educational programmes, skills training); staffing (named transition coordinators, joint clinics run by paediatric and adult physicians); and service delivery (separate young adult clinics, out of hours phone support, enhanced follow-up).
Limitations/weaknesses of review <i>As reported by authors</i>	The review is limited by the poor methodological quality of the studies. Analysis of the included studies was complicated by the multiple interventions delivered together without separate evaluation of different components and widely differing definitions and duration of interventions.  The heterogeneity of interventions, conditions and outcomes makes it very difficult to directly compare studies.
Any other comments	

<b>Dilek Y, Berna FE, Dilek K. 2011. Transition to adult for adolescent with chronic condition and strategies of nursing. Acta Paediatrica, International Journal of Paediatrics, 100, 131-132.</b>	
Relevant to review questions: 1? & 3	
<b>STUDY DESIGN:</b>	
Databases searched:	Medline, Pubmed, Wiley-Blackwell, Science-Direct
Years searched:	Not stated
Languages included:	Not stated
<b>REVIEW QUESTIONS:</b>	To describe the transition experience, expectations and concerns of chronically ill youth who have transitioned to adult health care.
<b>INCLUSION CRITERIA</b>	
POPULATION <i>e.g. age, sex, health condition, country</i>	Not specified.  Presumably, young people with chronic illness who have transitioned to adult health care.
INTERVENTION/ COMPARATORS	Not specified.  Transition process?
OUTCOMES	Not specified.
STUDY DESIGNS	Not specified.
FINDINGS	Not specified.  ? In order to achieve a high quality, co-ordinated service the aims of transitional care should be a service that is: Patient-centred; developmentally appropriate; responsive and comprehensive; promotes skills in communication, decision-making, assertiveness, self-care and self-advocacy; maximises life-long functioning; enhances sense of control and interdependence.
Limitations/weaknesses of review <i>As reported by authors</i>	Not specified.
Any other comments	Abstract only – need to contact authors for full report. Tried to do this but cannot find email address.

<b>Doug M, Adi Y, Williams J, Paul M, Kelly D, Petchey R, Carter YH 2011. Transition to adult services for children and young people with palliative care needs: a systematic review. Archives of Disease in Childhood, 96, 78-84.</b>	
Relevant to review questions: 1, 2 & 3	
<b>STUDY DESIGN:</b>	
Databases searched:	MEDLINE, CINAHL, PsychINFO, British Educational Index, International Bibliography of the Social Sciences
Years searched:	Jan 1995-Feb 2008
Languages included:	Not specified
<b>REVIEW QUESTIONS:</b>	<ol style="list-style-type: none"> <li>1. To evaluate the evidence on transition from child to adult services for YP with palliative care needs</li> <li>2. To explore the impact of the transition process on continuity of care, YP and their families' experiences</li> <li>3. To identify models of good practice</li> </ol>
<b>INCLUSION CRITERIA</b>	
POPULATION <i>e.g. age, sex, health condition, country</i>	<p>Young people aged 13-24 years with palliative care conditions (defined by author's criteria) in the process of transition.</p> <p>USA, UK, Australia, Canada, Denmark, Switzerland, Germany, Sth Africa</p>
INTERVENTION/ COMPARATORS	Other transition programmes/models
OUTCOMES	Not specified
STUDY DESIGNS	Varied methodologies including qualitative studies
FINDINGS	<p>Most predominant transition model was:</p> <ul style="list-style-type: none"> <li>• condition-specific model, e.g. Cancer, CF.</li> </ul> <p>Three further models described:</p> <ul style="list-style-type: none"> <li>• Paediatric service to adult service direct</li> <li>• Paediatric service to adult transition clinic to adult service</li> <li>• Paediatric service to adolescent clinic to young adults clinic to adult service</li> </ul> <p>Different transition models/processes proposed according to various conditions, grouped in terms of:</p> <ul style="list-style-type: none"> <li>• Life-threatening conditions</li> <li>• Life-limiting conditions</li> <li>• Severe, non-progressive neurological disability</li> <li>• Mixed palliative care conditions</li> <li>• Generic transition – key themes/strategies considered important for effective transition programmes and barriers identified</li> </ul> <p><b>Table of facilitators for a successful transition process</b> between child and adult healthcare professionals, health systems, YP, families and carers provided. The 3 principles that underpin a successful transition programme are information, communication and planning/coordination.</p>

	<p><b>Table of barriers</b> for child and adult healthcare professionals and health systems, YP, families and carers that affect the transition process provided. Factors that impede transition include service-based demands, restrictions in relation to service provision and personal preferences.</p> <p>Lack of standardised transition programmes and only few models of good practice.</p> <p>Fragmentation – poor continuity of care</p> <p>Significant differences between child and adult providers</p> <p>Role of family in transition seen as important – in particular, individualised, flexible transition plans that consider views of YP and families.</p> <p>Concern re. lack of access to and availability of appropriate comparable adult services for YP approaching transition.</p> <p>Appropriate education and training is essential for those providing care. Concepts of key worker and peer-led models of support need to be explored further.</p> <p>Additional issues relating to professionals, e.g. adult providers' inexperience re. YP care needs, paediatricians reticence to initiate transition process, etc.</p>
<p>Limitations/weaknesses of review</p> <p><i>As reported by authors</i></p>	<p>Meta-analysis of findings was not feasible due to heterogeneity of papers and limited measures of effectiveness/outcomes.</p> <p>Small sample sizes</p> <p>Limited transferability and generalizability of findings</p>
<p>Any other comments</p>	<p>Used a validated scoring system for systematically appraising empirical studies with varied methodologies, including qualitative studies.</p> <p>SPSSV.15 used to manage data extraction process and perform frequency analysis of search findings.</p>

<p><b>Fleming, E., Carter, B., Gillibrand, W. (2001). The transition of adolescents with diabetes from the children's health care service into the adult health care service: a review of the literature. Journal for Clinical Nursing 11 560-567</b></p>	
<p>Relevant to review questions: 2</p>	
<p><b>STUDY DESIGN:</b></p>	
<p>Databases searched:</p>	<p>CINAHL 1982-2001 and MEDLINE 1966-2001 plus reference list search</p>
<p>Years searched:</p>	<p>1966 to 2001</p>
<p>Languages included:</p>	<p>All literature accessed was available in English language</p>
<p><b>REVIEW QUESTIONS:</b></p>	<p>This review critically evaluates publications relating to the transition of young people from the children's health care service into the adult health care service. The review explores the barriers to the transition process and the principles that should be adopted for a successful transition</p>
<p><b>INCLUSION CRITERIA</b></p>	

<p>POPULATION <i>e.g. age, sex, health condition, country</i></p>	<p>Not clearly specified</p> <p>Adolescents/young people with diabetes undergoing transition to adult health care</p>
<p>INTERVENTION/ COMPARATORS</p>	<p>Not clearly specified</p> <p>Transition of young people from the children’s health care service to the adult health care service</p>
<p>OUTCOMES</p>	<p>Not specified in inclusion criteria</p> <ul style="list-style-type: none"> <li>• The unique health needs of adolescents with diabetes</li> <li>• Transition from the children’s health care service into the adult health care service</li> <li>• Barriers to the transition from the children’s health care service into the adult health care service</li> <li>• Adolescents’ perceptions of the transition into the adult health care system</li> <li>• Principles of a successful transition</li> </ul>
<p>STUDY DESIGNS</p>	<p>Not clearly specified</p>
<p>FINDINGS</p>	<p>Summary</p> <ul style="list-style-type: none"> <li>• Adolescents with diabetes have unique health needs, which impact upon their transition from children’s health care services into adult health care services.</li> <li>• These health needs result from the precarious period in their lives. This coincides with their move from the children’s into the adult health care service. Whilst coping with these pressures, they must also keep their diabetes under control</li> <li>• The impact of emotional and physical demands upon the adolescent means that they are more susceptible to non-adherence, which may result in reduced diabetic control</li> </ul> <p>1) The unique health needs of adolescents with diabetes Maturing into an adult provokes pressure that impacts on an adolescent’s management of their diabetes, providing the potential to become non adherent with treatment regimes</p> <p>2) Transition from the children’s health care service into the adult health care service Transition must be carefully managed so that the adolescent does not need to make an abrupt adaptation in their move from a supportive environment to one where they are expected to be independent.</p> <p>3) Barriers to the transition from the children’s health care service into the adult health care service e.g. parental emotions as barriers and physician resistance to the transition</p> <p>4) Adolescents’ perceptions of the transition into the adult health care system Ideal time for transition into the adult service was late in their teenage years or early in their twenties.</p>



	<p>Need for healthcare workers to possess effective interpersonal and communication skills.</p> <p>5) Principles of a successful transition Transition should be planned and coordinated, promotion of independence plays a key role in ensuring a successful transition</p> <p>Adolescents desire for more information: information about their condition and new developments, provision of emergency care and telephone advice</p> <p>The literature highlights the need for collaboration between children's and adult health care services, which will assist the structured care of adolescents.</p> <p>Children's teams should take a more family centred approach, whilst adult teams place greater emphasis on individual independence and autonomy</p> <p>Timing of transfer should take into account an adolescent's physical development and emotional maturity and occur at a time of relative stability in their health and be coordinated with other life transitions.</p>
<p>Limitations/weaknesses of review <i>As reported by authors</i></p>	<p>Limitations of primary studies: there is a lack of research exploring adolescents' perceptions of their transition into the adult service. The research available is scant, often with a limited target population, and at times lacks robust methodology.</p> <p>The authors do not comment on limitations of the review.</p>
<p>Any other comments</p>	<p>Not well structured/reported</p>

<p><b>Jalkut MK, Allen PJ. 2009. Transition from pediatric to adult health care for adolescents with congenital heart disease: a review of the literature and clinical implications. Pediatric Nursing 35, 381-387</b></p>	
<p>Relevant to review questions: 1,2 &amp; 3</p>	
<p><b>STUDY DESIGN:</b></p>	
<p>Databases searched:</p>	<p>CINAHL, Ovid Medline (Google Scholar)</p>
<p>Years searched:</p>	<p>CINAHL 1982-2009; Ovid Medline 1950-2009 (Google Scholar 2008)</p>
<p>Languages included:</p>	
<p><b>REVIEW QUESTIONS:</b></p>	<p>Review is focused on:</p> <ol style="list-style-type: none"> <li>1. Concept of transition in the context of health care for adolescents and young adults with CHD.</li> <li>2. Outcomes in adults with CHD.</li> <li>3. Implications for nursing and institutional practice.</li> </ol>
<p><b>INCLUSION CRITERIA</b></p>	
<p>POPULATION <i>e.g. age, sex, health condition, country</i></p>	<p>Adolescents, young adults and adults with congenital heart disease, involved in transition care in CHD and other chronic conditions and including physiological and psychological outcomes of adults with CHD.</p>
<p>INTERVENTION/ COMPARATORS</p>	<p>Other transition programmes.</p>
<p>OUTCOMES</p>	<p>Not specified.</p>

STUDY DESIGNS	Not specified.
FINDINGS	<p><b>Keys to successful transition</b></p> <p><b>Perspective of adolescent with chronic condition and family:</b></p> <ul style="list-style-type: none"> <li>• Reassure family there will be no interruption of care</li> <li>• Build confidence of YP related to self-management tasks</li> <li>• Inform family about adult services and give anticipatory guidance re. transition process starting in early adolescence</li> <li>• Recognise lack of trust, fear and anxiety related to acquiring new adult provider</li> <li>• Document communication between paediatric and adult providers</li> <li>• Take part in continuing education and professional training for paediatric and adult providers caring for YP with chronic conditions.</li> </ul> <p><b>Perspective of paediatric and adult providers caring for YP with chronic conditions:</b></p> <ul style="list-style-type: none"> <li>• Approach transition as 3-step developmental process spanning years and many visits</li> <li>• Identify differences between paediatric and adult care and give ongoing guidance re. what to expect</li> <li>• Establish trusting relationships between all involved. A family is more likely to trust an adult provider if they perceive a trusting relationship between paediatric and adult provider</li> </ul> <p><b>Role of Paediatric Nurse Practitioner (PNP) as Transition Coordinator</b> – Most successful transition programmes have a PNP to lead YP through transition process.</p> <p><b>Health passport</b> – a health passport is seen as essential to successful transition.</p> <p><b>Barriers to successful transition:</b> Lack of understanding of condition and potential complications/prognosis in YP. Lack of education and guidance.</p> <p>Concerns of adult clinicians in transitioning young adults from paediatric to adult care</p> <ol style="list-style-type: none"> <li>1. Concerns regarding young adult’s ability to assume care: <ul style="list-style-type: none"> <li>• Maturity of the young adult to adhere to management plan</li> <li>• Psychosocial needs of young adults with chronic conditions</li> <li>• Need for family to be involved</li> <li>• Ability of young adult to assume decision-making responsibility</li> <li>• Young adult often ignorant of morbidity of condition and need for care</li> </ul> </li> <li>2. Concerns regarding the clinician’s competence in providing care: <ul style="list-style-type: none"> <li>• Lack of training in condition</li> <li>• Need for condition-specific specialist</li> <li>• Time needed to provide care</li> <li>• Lack of knowledge and experience working with YP</li> <li>• Difficulty facing disability/end of life issues with YP</li> </ul> </li> </ol>
Limitations/weaknesses of	Confusion relating to classification of CHD – difficult to compare

review <i>As reported by authors</i>	outcome and transition data across studies. Studies conducted based on medical record review or questionnaires reflecting only those individuals receiving care – therefore, lack of outcomes and morbidity/mortality data from those lost to follow up.
Any other comments	Focus on USA. Some issues not relevant, e.g. insurance recommendation from paediatric clinician

<b>Jones, S.E., Hamilton, S. (2008) The missing link: paediatric to adult transition in diabetes services, British Journal of Nursing, 17 (13), 842-847</b>	
Relevant to review questions: 1, 2, 3	
<b>STUDY DESIGN:</b>	
Databases searched:	Medline (1980-2007), CINAHL (1982-2007) British Nursing Index (1994-2007), Cochrane Library (all evidence based medicine reviews), BioMed Central (earliest to 2007) and Applied Social Sciences Index and Abstracts (earliest to 2007)
Years searched:	1980 to 2007
Languages included:	English
<b>REVIEW QUESTIONS:</b>	Not clearly specified  Gives an overview of issues, barriers and facilitators to successful transition and touches on models for transition of care.
<b>INCLUSION CRITERIA</b>	
POPULATION <i>e.g. age, sex, health condition, country</i>	Studies must be focused on the transition period in adolescence. Diabetes
INTERVENTION/ COMPARATORS	Not specified
OUTCOMES	Studies reporting patient/participant experiences
STUDY DESIGNS	All research designs were included to ensure that studies reporting patient/participant experience and views were incorporated into the review
FINDINGS	Five themes were identified: Adolescence as a time of transition Adolescent needs during transition Barriers Facilitators Models of transition  Key findings: <ul style="list-style-type: none"> <li>• The transition process remains problematic with a gap between paediatric and adult services being identified, including significant differences in clinical practice and culture.</li> <li>• Although there is a growing body of knowledge around the reasons behind this phenomenon, research into effective models of transition to address these problems is still lacking</li> <li>• A period of managed transition between the two services has been recommended, with evidence that the nurse has</li> </ul>

	the potential to develop a coordinating role, to assist in bridging the gap between paediatric and adult services
Limitations/weaknesses of review <i>As reported by authors</i>	Not reported
Any other comments	

<b>Lugasi, T., Achille, M., Stevenson, M. (2010) Patients' Perspectives on Factors That Facilitate Transition From Child-centered to Adult-centered Health Care: A Theory Integrated Metasummary of Quantitative and Qualitative Studies</b>	
Relevant to review questions: 3 + 2	
<b>STUDY DESIGN: SR</b>	
Databases searched:	MEDLINE, PsychINFO, CINAHL - increased the database searches by scrutinizing the retrieved articles' references to identify additional relevant publications. Search last updated in April 2009
Years searched:	Last 15 years
Languages included:	Be published in English or French peer-reviewed journal
<b>REVIEW QUESTIONS:</b>	Objectives (1) to describe the state of the empirical transition literature completed until recently pertaining to chronically ill adolescent and young adult patients and (2) to identify factors that potentially lead to a smoother transition to ACC (Adult-centred care)
<b>INCLUSION CRITERIA</b>	
POPULATION <i>e.g. age, sex, health condition, country</i>	1) Focus on adolescents and /or young adults with a physical chronic illness  Excludes mental illness e.g. ADHD, autism learning disabilities or cognitive impairments
INTERVENTION/ COMPARATORS	Does not specify
OUTCOMES	Examine patient's transition experience, before or after the transfer took place
STUDY DESIGNS	Studies using quantitative or qualitative methodology
FINDINGS	Empirical results on transition fall into four groups: 1) patients' feelings and concerns: 2) patients' recommendations about transition; 3) outcomes after transfer; 4) mode of transfer  1) Patients feelings and concerns Attachment issues to current health care providers Concerns: quality of care in adult-centred care, lack of knowledge, not knowing what to expect, not liking the environment, not trusting ACC providers, transfer of medical records  2) Patients recommendations Patient choice and control Need for independence Preparation towards transition  3) Outcomes after transition Satisfaction after transition – positive: having more control over decision making, feeling more responsible for the management of

	<p>their condition.</p> <p>Negative: loss of relationships, fear for their future seeing older sicker patients, feeling of lack of knowledge, lack of continuity. Lack of coordination between CCC and ACC, not receiving enough information before transfer</p> <p>4) Adherence after transition Attendance to medical follow ups, suffers a decline after transfer to ACC</p> <p>5) Mode of transfer Patients most satisfied with their transition were those who had been transferred to an adult clinic within the same hospital and met the providers before</p>
<p>Limitations/weaknesses of review</p> <p><i>As reported by authors</i></p>	<p>Focused solely on physical chronic illnesses and results cannot be generalised to other conditions for which transition to ACC represents an issue. Difficult to ascertain that the results are generalizable to each condition equally. Possibility missed research studies in search.</p> <p>Important studies may have been missed</p>
Any other comments	

<b>Machado DM, Succi RC, Turat ER. Transitioning adolescents living with HIV/ AIDS to adult-oriented health care: an emerging challenge. Journal de Pediatria 2010; 86 (6): 465-72</b>	
Relevant to review questions: 1, 2	
<b>STUDY DESIGN:</b>	
Databases searched:	MEDLINE, LILACS
Years searched:	1990 - 2010
Languages included:	English and French
<b>REVIEW QUESTIONS:</b>	Not stated. Objective of review was to review the topic of transition, with a particular focus on adolescents living with HIV/ AIDS.
<b>INCLUSION CRITERIA</b>	
POPULATION <i>e.g. age, sex, health condition, country</i>	Not stated - Presumably adolescents living with HIV/ AIDS
INTERVENTION/ COMPARATORS	Not stated - Presumably transition models
OUTCOMES	Not stated
STUDY DESIGNS	Not stated.
FINDINGS	Several authors agree that transitioning adolescents to adult-oriented healthcare should be a gradual process not determined by age alone. It requires a plan established with ample dialogue among adolescents, their families and paediatric and adult care teams. However, there is little evidence to support any specific model of health care transition.

	<p>Barriers: abrupt transfer with little or no prior preparation; poor or absent planning; resistance on the part of patients, family members or pediatric care providers; delay in booking appointments at adult clinic after transfer from pediatric service; poor preparedness on the part of adult-orientated services to receive and treat young adults with childhood-onset chronic conditions; differences in care between pediatric services (supportive, family centred approach) and adult oriented services (individual independence expected); poor or absent communication between pediatric and adult-oriented services; poor or absent institutional support.</p> <p>Recommendations for good transition practices: transition planning should be regarded as an essential component of care quality in adolescent-oriented services; patient records should be easily accessible to the receiving team; services should be flexible and focus on young patients' needs; each general or specialist paediatrician should have a specific policy for transition; more formal transition programs are required in facilities with a large contingent of adolescents being transferred to adult-oriented services; youths should not be transferred unless they have the conditions to attend an adult-oriented service and are past the growth and puberty stages; one person each from the pediatric and adult-oriented teams should be in charge of managing the transition; good communications and connections between both services are a requirement; large pediatric services should develop a 'transition roadmap' detailing how and where the process occurs in each specialty.</p>
Limitations/weaknesses of review <i>As reported by authors</i>	None reported.
Any other comments	No methods section.

<b>Nakhla, M., Daneman, D., Frank, M., Guttman, A. (2008). Journal of Paediatric Endocrinology and Metabolism, 21 (6), 507-516</b>	
Relevant to review questions: 3 + 1	
<b>STUDY DESIGN: SR</b>	
Databases searched:	Medline (1950-2007), CINAHL (Cumulative Index to Nursing & Allied Health, 1982-2007) and EMBASE (1980-2007)
Years searched:	1950-2007
Languages included:	Not reported
<b>REVIEW QUESTIONS:</b>	Not reported specifically  Purpose of this paper is to review the diabetes literature as it pertains to transition including outcomes, methods and patient's perceptions of the transition period
<b>INCLUSION CRITERIA</b>	
POPULATION <i>e.g. age, sex, health condition, country</i>	Adolescents with diabetes undergoing transition
INTERVENTION/ COMPARATORS	Different transition models within four health districts in Oxford UK region

OUTCOMES	Description of outcomes following transition including perceptions of the transition process and evaluation of the models of transition care
STUDY DESIGNS	Most articles were not true cohort studies but rather case series and descriptive reports
FINDINGS	<p>Decrease in diabetes care visits following transition and factors such as poor glycaemic control, presence of diabetes related hospitalisations and poor clinic attendance in the year prior to transfer appear to be good predictors of poor clinic attendance after transfer.</p> <p>The impact of these outcomes on glycaemic control and diabetes-related complications has not been studied.</p> <p>Perceptions of transition process: Time constraints were cited as main reason for lack of attendance at adult clinics. Felt they should have more flexible hours and shorter waiting times for appointments and have clinics in the evenings.</p> <p>Patient experiences: Felt a sense of abandonment by the paediatric team, for a smoother process they would prefer longer initial meetings with the adult diabetes team or have had visits with the adult team prior to being transferred to adult care. Their 'ideal' diabetes centre should not be in a hospital setting and staff should be approachable and understand the issues of young people</p> <p>Models of transition</p> <ol style="list-style-type: none"> <li>1) Direct transfer to an adult clinic</li> <li>2) Transfer to a young adult clinic in a different hospital</li> <li>3) Transfer to a young adult clinic within the same hospital with introduction to the adult physician prior to transfer</li> <li>4) Transfer to an adult clinic run jointly by paediatric and adult physicians</li> </ol> <p>No consensus on the most appropriate method of transition but improvement in clinic attendance may be achieved through</p> <ol style="list-style-type: none"> <li>1) Implementing an educational transition programme</li> <li>2) Having a transition care coordinator</li> <li>3) Having a young adult transition clinic attended by both adult and paediatric physicians</li> </ol>
Limitations/weaknesses of review <i>As reported by authors</i>	Studies on transition care were limited by their small sample sizes and by selection and information biases
Any other comments	Used SIGNS (Scottish Intercollegiate Guidelines Network) grading for cohort studies as a framework for assessing quality of studies. They were unable to assign a specific grade to the articles as most were not cohort studies.

<b>Pai ALH, Ostendorf HM 2011. Treatment adherence in adolescents and young adults affected by chronic illness during the health care transition from paediatric to adult health care: a literature review. Children's Health Care, 40: 16-33.</b>	
Relevant to review questions: 2, 3	
<b>STUDY DESIGN:</b>	
Databases searched:	PsychLit, Medline and CINAL
Years searched:	1969-2009
Languages included:	Does not state
<b>REVIEW QUESTIONS:</b>	<p><b>This review:</b></p> <ul style="list-style-type: none"> <li>a) Describes treatment adherence during the Health Care Transition (HCT) period</li> <li>b) Describes the relations between individual and system factors and treatment adherence during the HCT period</li> <li>c) Reviews existing intervention methods and identifies directions for future research on adherence during the HCT</li> </ul> <p>Considers the potential clinical applications for adherence management during the HCT based on the best available scientific data compiled from HCT and treatment adherence research</p> <p>Studies were also excluded if they only examined adherence among cancer survivors</p>
<b>INCLUSION CRITERIA</b>	
POPULATION <i>e.g. age, sex, health condition, country</i>	Adolescents and young adults affected by a chronic illness during the HCT
INTERVENTION/ COMPARATORS	Studies that examined HCTs among adolescents and young adults with a chronic illness
OUTCOMES	Treatment adherence during the HCT among adolescents and young adults affected by a chronic illness
STUDY DESIGNS	<p>One cross-sectional, six longitudinal, six retrospective, one pre-intervention, and one post intervention - qualitative and quantitative studies.</p> <p>Studies that did not include a measure of adherence or did not include systematic qualitative or quantitative data (i.e. reviews, editorials and commentaries) were excluded</p>
FINDINGS	<p>Chronic illnesses of 12 included studies included:</p> <ul style="list-style-type: none"> <li>Type 1 diabetes</li> <li>Solid organ transplant</li> <li>Cystic Fibrosis</li> <li>Asthma</li> </ul> <p>(In summary)</p> <p>The HCT is a critical period for establishing patterns of treatment adherence and health outcomes and therefore, warrants heightened clinical and research attention.</p> <p>Several factors were identified that contribute to non-adherence during the HCT including age of the patient, poor psychological adjustment, unfamiliarity with the paediatric and adult health care systems, and financial barriers. Although some critical factors have been identified that are related to adherence during HCT there are a number of critical questions that remain unanswered</p>



	<p><b>Non adherence during the HCT period</b>  Studies have demonstrated that treatment adherence declines across a number of treatment domains including attendance at clinic appointments, oral medication adherence and other illness specific tasks. These patterns are concerning because poor adherence has been related to the development of otherwise preventable medical complications and adverse health outcomes in adolescents and young adults with chronic illnesses</p> <p><b>Factors related to adherence outcomes during the HCT period</b>  To date developmental, individual and systems factors have been associated with treatment adherence and health outcomes:  Developmental factors  Psychological factors  Family factors  Systemic factors  Financial factors</p> <p><b>Interventions to facilitate adherence during HCTs</b>  Recommendations or interventions to facilitate successful transition programmes have included identifying a designated transition coordinator, patient education, identification of a capable adult physician, health care planning focused on access to health insurance, development of self-management skills, and flexible timing of the transition process.  Few recommendations/programmes explicitly focus on treatment adherence and even fewer have been empirically tested.</p>
<p>Limitations/weaknesses of review  <i>As reported by authors</i></p>	<p>The most significant limitation is the reflection of the current state of the literature. Relatively few studies examining HCTs incorporated measures of adherence. Therefore this review includes a limited number of studies that represent early examples of research in this area. There are multiple treatment regimens (e.g. dietary regimens) and factors (e.g. family conflict, illness type, and treatment complexity) that could influence treatment adherence during HCT that were not examined here. This review is susceptible to the effects of potential publication bias against studies that did not have significant results.</p>
<p>Any other comments</p>	

<p><b>Watson R, Parr JR, Joyce C, May C, Le Couteur AS. 2011. Models of transitional care for young people with complex health needs: a scoping review. Child: Care, Health and Development. 37: 780-791</b></p>	
<p>Relevant to review questions: 1</p>	
<p><b>STUDY DESIGN:</b></p>	
<p>Databases searched:</p>	<p>MEDLINE, EMBASE, CINAHL, SCOPUS</p>
<p>Years searched:</p>	<p>1980- April 2010</p>
<p>Languages included:</p>	<p>English only</p>
<p><b>REVIEW QUESTIONS:</b></p>	<p><b>AIMS:</b>  To identify models of transitional care from child to adult health services for cerebral palsy, autistic spectrum disorder and diabetes.   To seek evidence to inform 'best practice' about transitional care for children with complex health needs.</p>

	<p>To investigate whether the identified models of transitional care have been evaluated.</p> <p>To use Normalisation Process Theory to evaluate whether aspects of service sustainability had been considered.</p>
<b>INCLUSION CRITERIA</b>	
POPULATION <i>e.g. age, sex, health condition, country</i>	Young people (14-25 years) with cerebral palsy, autistic spectrum disorder and diabetes, transferring from child to adult health services.
INTERVENTION/ COMPARATORS	Models of transitional care: 'model' defined as clear description of new or existing transitional care arrangements from child to adult healthcare services for young people aged 14-25 years.
OUTCOMES	Not specified in inclusion criteria.
STUDY DESIGNS	Not specified in inclusion criteria.
FINDINGS	<p>19 papers reporting 18 service models were included. A very limited literature of models of service provision was identified for young people with cerebral palsy and diabetes. No models were identified for young people with autism spectrum disorders. Furthermore most publications were either descriptions of new service provision or time-limited pilot studies with little service evaluation or consideration of key elements of effective implementation.</p> <p>Most papers focused on the need to provide an individualised healthcare plan for each young person and two thirds of studies reported an understanding of the need for flexibility in the timing of transfer. Only 8 of the 18 models considered other aspects of adolescent development. Four papers provided some information about sustainability such as future planning or funding of the service. Sustainability was usually discussed as a problem of securing funding. Most studies reported disease specific outcomes over less than six months. Only six papers presented comparative data.</p>
Limitations/weaknesses of review <i>As reported by authors</i>	Evidence from other medical conditions was not sought. Search strategies may have "inadvertently excluded" some relevant publications or models due to non-standard MeSH terms for transition and transfer. Limited to what is reported in publications (may be more information that is unpublished). Other models may not have been evaluated or published yet.
Any other comments	Scoping review. English language only. Focuses on technique of Normalisation Process Theory.

<b>While A, Forbes A, Ullman R, Lewis S, Mathes L, Griffiths P. 2004. Good practices that address continuity during transition from child to adult care: synthesis of the evidence. Child: Care, Health and Development, 30: 439-452.</b>	
Relevant to review questions: 1, 3	
<b>STUDY DESIGN:</b>	
Databases searched:	A broad range including specialist – not specified. Addition of SIGLE (grey literature)

Years searched:	Last 20 years (search completed in June 2001)
Languages included:	Mainly English language, a number of mainly European papers were translated
<b>REVIEW QUESTIONS:</b>	<p>Reports findings of a systematic examination of the evidence regarding good practice models at transition</p> <p>Objectives:</p> <ol style="list-style-type: none"> <li>1) Identify literature, research and practice relevant to the scope of the review following an explicit search strategy</li> <li>2) Critically appraise the items identified in the search</li> <li>3) Identify key components of good practice for promoting continuity</li> </ol>
<b>INCLUSION CRITERIA</b>	
POPULATION <i>e.g. age, sex, health condition, country</i>	<p>Review focused on five tracer conditions at transition: diabetes mellitus, learning disability, cystic fibrosis, congenital heart disease and muscular dystrophy</p> <p>UK, North America, Europe (other than UK), Australasia, South Africa, International</p>
INTERVENTION/ COMPARATORS	Practices relating to continuity or management of transition, good practice models
OUTCOMES	<ol style="list-style-type: none"> <li>1) Identifying practices</li> <li>2) Critically appraising practices</li> <li>3) Identifying the key components of good practice</li> </ol> <p><i>An item assessment schedule was 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 subcomponents; where the practice was located; structure, process and outcome variables; economic data; the role and involvement of users</i></p>
STUDY DESIGNS	Not specified in inclusion criteria
FINDINGS	<p><b>Overview of items:</b></p> <p>Descriptions User accounts- comprised questionnaire or interview surveys of limited rigour Reviews- theoretical discussions with reference to specific practice recommendations Evaluations – all those that attempted to assess the process of the outcome of the intervention</p> <p>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 young person's strengths for future development</p> <p>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</p>

	<p>Service development framework: core principles:</p> <ol style="list-style-type: none"> <li>1. Identify care group of user population</li> <li>2. Identify the key dimensions of transition</li> <li>3. Bring stakeholders together</li> <li>4. Identify transitional needs</li> <li>5. Transitional planning and agreement</li> <li>6. Identify/provide the resources</li> <li>7. Audit and Evaluation</li> </ol> <p><b>4 models identified:</b></p> <p><b>1. Direct transition model-</b> Continuity achieved when YP transferred to adult care safely and efficiently. Emphasis on communication and information sharing. Relations between service4s and addresses continuity of information and cross boundary and team continuity.</p> <p><b>2. Sequential transition model-</b> Recognises that young person’s needs are changing and require some preparation if they are to adjust to adult care successfully. Flexible and longitudinal continuity are addressed. May involve redefining of family role with YP being given increased autonomy in decision making about their care.</p> <p><b>3. Developmental transition model –</b> Starts from the premise that the YP will need some help in acquiring the skills and support systems necessary with adult care. Focus on personal growth and development with the transition-developmental continuity. Most relevant regarding services for vulnerable YP and those with physical disabilities or learning difficulties.</p> <p><b>4. Professional transitional model-</b> Focus on how 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. Important in conditions with a short life expectancy or where expertise is heavily located within one service, e.g. CF, HIV or AIDS.</p> <p>The models highlight two important continua:</p> <ol style="list-style-type: none"> <li>1. The focus continuum: young person-service.</li> <li>2. The developmental process continuum: implicit-explicit.</li> </ol>
<p>Limitations/weaknesses of review</p> <p><i>As reported by authors</i></p>	<p>The findings and proposed models are limited by the scope of the review and in particular the focus on explicit practices together with the absence of high quality primary material available for analysis</p>
<p>Any other comments</p>	<p>Material was also sought from experts in the field. A discussion of the method if reported in Forbes and Griffiths (2002)</p> <p>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 (Forbes and Griffiths 20012). The scoring systems within these schedules indicated the method as</p>

	either 'weak', 'moderate' or 'strong'
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#### Primary studies

<b>Betz et al 2010. Testing the transition preparation training program: A randomized controlled trial, <i>Int J Child Adolesc health, 3 (4), 595-607</i></b>	
Country: USA	
Relevant to review questions: 1, 2	
Study design: Prospective Randomised Controlled Trial	
Method of data collection <i>e.g. 15 Semi structured interviews &amp; 2 focus groups</i>	<p>The data collection period was from September 2006 to September 2008.</p> <p>Pre and post intervention data were collected from both groups of youth and their parents at baseline (T1) and 4 months later (T2). Post treatment data (T2) were collected at 4.1 months</p> <p>Parents completed the Personal Adjustment and Role Skills Scale (PARS III) and parent version of the TDQ (The Transition Questionnaire Youth and Parent versions).</p> <p>Adolescents completed five subscales of the CLSS – Community Life Skills Scale, the DSCPI-90© - Denyes Self-Care Practice Instrument. And the youth version of the TDQ – Transition Questionnaire Youth and Parent Versions.</p>
<b>INTERVENTION</b>	
Name/ nature of model (if described)	<p>The goal of the prospective controlled trial, as part of a larger study, was to examine whether a cognitive-behavioural programme of Transition Preparation Training (TPT), in combination with Spina Bifida management, leads to improved transition subjective wellbeing, role mastery and self-care practice.</p> <p>The Transition Preparation Training Programme was a 3 module, 8 session programme offered in a 2 day workshop format that involved the development of an adolescent-centred transition plan (Transition Roadmap to the Future) based on a comprehensive assessment of the adolescent's goals for the future.</p> <p>Module One (2 sessions) involved a comprehensive assessment of the adolescent's goals and dreams for the future related to health, school, work, community living, housing, recreation and leisure. This assessment was an interactive process led by the trainer involving the adolescent and other adolescent members of the group.</p> <p>Module Two (2 sessions) involved creating a comprehensive transition plan to achieve the adolescent's goals for the future, based upon the Module One assessment. The plan included identification of service needs, service referrals and contact information.</p> <p>Module Three (4 sessions) provided adolescents with SB with learning opportunities to practice strategies for obtaining the services they identified in their transition plan. A number of instructional strategies were used that included the following: role playing, one-to-one consultation, coaching, reinforced learning, use of audio visual aids, accessing the internet and mentored learning.</p>

Theoretical model (if given)	Not given
Condition <i>e.g. diabetes</i>	Spina Bifida (SB)
Comparator?	Compared adolescents with SB who received TPT in combination with SB management to adolescents with SB who received only SB management.
Setting	Children's Hospital Los Angeles
Who delivered it?	Intervention Team at Children's Hospital Los Angeles
<b>POPULATION</b>	
Target recipients ( <i>who it was aimed at</i> ) <i>e.g. age, sex, health condition</i>	<p>Inclusion criteria for population:</p> <ul style="list-style-type: none"> <li>a) Age 14- 18 years</li> <li>b) Diagnosis of SB</li> <li>c) English speaking</li> <li>d) No history of intellectual disability or mental illness</li> <li>e) Willingness to complete questionnaires independently or with surrogate assistance</li> </ul> <p>Inclusion criteria for parents:</p> <ul style="list-style-type: none"> <li>a) Has child with SB age 14-18 years</li> <li>b) English or Spanish speaking</li> <li>c) Mother/Father/Non-related Guardian of youth in the study's treatment or control groups</li> </ul> <p>Out of 65 adolescents with SB in sample: 31 in treatment group (mean age 16.19), 34 in control group (mean age 15.71).</p>
Outcomes for individuals: <i>List outcomes, how each was measured (e.g. scale), who measured it and when it was measured.</i>	<p>Subjective wellbeing as measured by the Personal Adjustment and Role Skills Scale (PARS III)</p> <p>Role Mastery measured using the Community Life Skills Scale (CLSS)</p> <p>Self Care Practice with the Denyes Self-Care Practice Instrument (DSCPI-90©)</p> <p>The Transition Questionnaire Youth and Parent Versions (TDQ) (developed by the investigators).</p>
Clinical/health outcomes	<p>No significant differences were found between groups of any treatment effect or treatment follow up interaction.</p> <p>No substantial changes in the scores either between treatments or post treatments were found.</p>
Service delivery, organisational outcomes. <i>List outcomes</i>	Not reported
<i>Whose perspective?</i> <i>List whose views, if any, are reported (e.g. patients, parents, caregivers)</i>	None
Costs/economic matters <i>State whether paper contains any economic info.</i>	None
Key process issues - Barriers	Youth showed lack of adherence with their transition plan follow-through. Forgetting to follow-through with their transition plan service referrals was a problem. Others were unclear as to what actions they needed to undertake based on their plan, following the first workshop.

	<p>Many youth were uncomfortable to ask questions for clarification during the first workshop. For others issues arose during the interim period that could not be resolved until the second workshop. The intervention did not include booster sessions to address these questions or issues mentioned previously. Regularly scheduled booster sessions between the formal educational sessions would have the effect of reminding, encouraging and troubleshooting with the youth to increase adherence to their transition planning goals.</p> <p>It became evident that the time frame was insufficient to effect the change that youth identified in their transition plan. The goals identified by youth were based on long-range plans that would only be accomplished over a period of months, and even years. The one month time frame of intervention model was insufficient to address these goals as the plan of action would extend for months and years beyond the intervention.</p> <p>Communication problems with providers existed in part as parents were reluctant to share information or they were unable to fully understand the providers' health guidance.</p> <p>Parent concerns about facilitating their children's access to transition supports were apparent during the study.</p> <p>Follow-up dates for data collection were delayed due to problems with contacting subjects by phone/email and unexpected issues preventing scheduling of appointments. This level of effort called into question the intervention's cost effectiveness and efficiency.</p> <p>They discovered a burden of responsibilities youth bore for learning the navigation skills needed to access services and supports. Parents were unable to provide support needed for the transition to adult systems of care due to their lack of knowledge of these systems, inability to speak English, low literacy levels and pressing family needs.</p>
Key process issues – facilitating factors	n/a
Key issues for young people	n/a
Recommendations for successful transition	<p>Recommended changes to their model Reconfigure the goal-setting of the youths individualised transition plans to more basic precursor levels of knowledge and skill.</p> <p>Increase the strength of the intervention dose with additional sessions to address learning needs and to reinforce learning may have been needed to demonstrate intervention effectiveness.</p> <p>Workshops to coincide with clinic visits or online training programmes may be more viable training options to overcome the obstacles associated with real-time scheduled weekend training workshops.</p> <p>Booster sessions involving one-to-one contact via email, text messaging or telephone contact involving the intervention team</p>

	<p>initiated either by the subject or team member may have been helpful. Regularly scheduled booster sessions between the formal educational sessions would have the effect of reminding and troubleshooting with the youth to increase adherence to transition planning goals.</p> <p>Intervention outcomes may be better operationalized with the use of more focused and time-limited behaviours such as enrolment in a youth-employment programme rather than the long-term adulthood goal of employment.</p> <p>They believe a delivery model modification to an online electronic format, with booster sessions using a longitudinal design warrants testing.</p>
Any negative impacts reported? <i>Yes/ No</i> <i>Individual/ organisational etc.</i>	None
Limitations/weaknesses of study <i>As reported by authors</i>	<p>The availability of empirically sound tools is limited. Some of the tools used in this study did not have the level of specificity and sensitivity needed.</p> <p>The research implications of this study reveal the limitations of this piloted model for application as a real-time intervention. The challenges identified with this intervention model revealed that it is not feasible clinically or economically.</p>
Any other comments	

<b>Cadario et al 2009. Transition process of patients with type 1 diabetes (T1DM) from paediatric to the adult health care service: a hospital based approach. Clinical Endocrinology 2009; 71: 346-350</b>	
Country: Italy	
Relevant to review questions: 1, 3	
Study design: Retrospective case review with quantitative and qualitative methods	
Method of data collection <i>e.g. 15 Semi structured interviews &amp; 2 focus groups</i>	<p>Retrospectively reviewed database of 62 adolescents and young adults discharged from the paediatric diabetes service (PDS) from 1994 to 2004 to the adult diabetic service (ADS) of the same hospital.</p> <p>All participants in groups A and B were invited to answer a questionnaire directly or by telephone, delivered by a nurse in the PDS, concerning their experiences of transition.</p>
<b>INTERVENTION</b>	
Name/ nature of model (if described)	No name given. The study involved comparing an unstructured vs structured transition programme for two groups of patients from paediatric to adult diabetic services in the same hospital
Theoretical model (if given)	none
Condition <i>e.g. diabetes</i>	Type 1 diabetes
Comparator?	Group A (32 patients) were transferred to the ADS of the same hospital with an unstructured method: discharged at the end of adolescence with a letter summarising their clinical history and with a fixed appointment in the ADS. Group B (30 patients) were transferred with a structured transition planned with adult physicians.
Setting	Adult Diabetic Service at Maggiore della Carita Hospital, Novara, Italy



Who delivered it?	Paediatric Diabetes Service – Transition coordinator paediatrician working with an endocrinologist and adult physicians. Paediatric diabetes specialist acted a transition coordinator.
Description of model/ intervention	<p>They identified 2 groups:</p> <p>Group A comprised patients discharged at the end of adolescence from 1st January 1994 to 31 December 1999 with an unstructured transfer - by a letter summarising their clinical history and with a fixed appointment in the ADS.</p> <p>Group B comprised patients discharged at the end of adolescence from 1st January 2000 to 31 December 2004 with a structured transition programme planned with endocrinologists of the ADS. The structured programme commenced in February 1999 and involved 18 to 20 year old patients. They anticipated or delayed transition according to certain conditions: <i>If an 18 year old had recently been diagnosed with T1DM then transition was delayed and if a relative of theirs had already been affected by T1DM and followed into ADS they anticipated transition earlier?</i></p> <p>A single patient coordinator qualified as a paediatric expert in diabetes followed the patients during their paediatric care and into the transition programme working with the same endocrinologist. In the structured programme, eligible patients were informed about the transition during their last year in PDS, with clear explanations about the process and clinical implications at each visit. A letter describing the event was handed to all patients and discussed with the paediatrician during the next to last visit in PDS; all group B patients were guaranteed continuing individual assistance through the whole process, and for the possibility to go back, if they didn't like the ADS.</p> <p>The last visit in PDS of each patient was done jointly with the endocrinologist of the adult staff without the presence of patients' parents. Patients referred to the ADS did not routinely meet the adult endocrinologist before their last visit to PDS.</p> <p>During the last visit in PDS patients were visited by paediatrician and endocrinologist together.</p> <p>The paediatrician also gave a conclusive letter and a programmed file to both adult physician and transferred patients.</p> <p>The first visit in ADS was done in the presence of the paediatrician; patients were visited together but formal prescription was given by the adult endocrinologist.</p> <p>All participants were grouped together in the first year of follow up in the ADS; younger patients were considered separately from the older ones</p>
Support given/ level of supervision	No support in the unstructured transition for group A, group B were supported by a transition coordinator (paediatrician) working with an endocrinologist and adult physician.
When was intervention delivered/ patient pathway <i>what stage intervention takes place- e.g. before transition</i>	<p>Intervention was started before transition.</p> <p>Retrospectively reviewed adolescents discharged from PDS to ADS: Group A included adolescents discharged from the PDS from 01/01/94 to 31/12/1999</p> <p>The structured transition programme commenced in February 1999 for group B</p> <p>Group B included adolescents discharged from the PDS to ADS from 01/01/00 to 31/12/04.</p> <p>Review their transition period from the last year of PDS to three</p>

	years after transition in ADS (HbA1c %)
<b>POPULATION</b>	
Target recipients ( <i>who it was aimed at</i> ) e.g. age, sex, health condition	62 adolescents and young adults discharged from the paediatric diabetes service from 1994 to 2004 to the adult diabetic service of the same hospital. Age of target population: mean 19 +- 2.8 years (SEM) Age at transfer: group A: 17.8 +- 1.5, group B: 19.1 +-1.0 Sex: group A: 18 males/14 females, group B: 16 males/14 females Condition: Type 1 Diabetes Mellitus
Individual outcomes <i>List outcomes, how each was measured (e.g. scale), who measured it and when it was measured. Use another form for actual results?</i>	<p>Outcomes:</p> <p>Clinic attendance rate – measured by analysing the clinic database and using dates of discharge from PDS and admissions to ADS and calculating clinic attendance rates as a percentage of regular turn ups at visits</p> <p>Mean HbA1c % in the last year in PDS and first year of ADS – clinic database</p> <p>Experience of transition – qualitative interview by telephone or directly by nurse of the PDS – after transition.</p> <ol style="list-style-type: none"> <li>1. Medical care during the transition process</li> <li>2. Insulin prescriptions</li> <li>3. Frequency of physical examinations</li> <li>4. Assessment of glycaemia tests</li> <li>5. Retinal and foot screening</li> <li>6. Number of HbA1c determinations and microalbuminuria tests for one year</li> <li>7. Last changes in insulin therapy (self made or proposed by GP or endocrinologist)</li> </ol> <p>Patients were asked to rate their transition experience qualitatively as good/sufficient/bad</p> <p><b>Results</b></p> <p>Group A: 32 participants, group B: 30 participants. 92% of patients answered questionnaire (84% group A and 100% group B)</p> <p>During the unstructured transition, in group A all the subjects lacked specialist follow up and young patients attended only their GP for insulin prescriptions (29.6% vs 0, <math>p &lt; 0.001</math>), and more carried out self care without nurse assistance (70.3% vs. 0, <math>p &lt; 0.0001</math>).</p> <p>Group A compared with group B had a break in clinical examinations (55.5% vs. 0, <math>p &lt; 0.001</math>) and laboratory examinations (74.1% vs. 0, <math>p &lt; 0.001</math>) during the transition period.</p> <p>Both groups rated their experience in PDS as good, all subjects in group B reported favourable judgement for the structured transition, compared to poor opinion for the unstructured transition in 19 out of 27 (70.3%) patients of group A (<math>p &lt; 0.001</math>).</p> <p><b>Metabolic and clinical outcomes</b></p> <p>The time between their last visit in PDS and their first visit in ADS was significantly shorted in group B than group A. One year after transition from PDS, 31% (10/32) of the subjects in group A and nearly 100% (29 out of 30) of group B were entered into ADS care.</p>

	<p>Three years after their last visit in ADS, 73% of subjects in group A and 100% of group B were still followed in ADS (<math>p &lt; 0.05</math>).</p> <p>The first HbA1c in ADS was improved in group B compared to the mean of HbA1c in their last year in PDS (7.9 +/- 1.0% vs. 9.1 +/- 0.4%, <math>p &lt; 0.01</math>), (This was just after transition period and without any change in prescription in the ADS), while there were no changes to HbA1c in group A (8.4 +/- 1.3% vs. 8.9 +/- 0.8%, <math>p = n.s.</math>).</p> <p>One year after the transition period, the mean HbA1c was lower in group B than A participants (7.8 +/- 0.5% vs. 8.9 +/- 0.5%, <math>p &lt; 0.1</math>).</p> <p>One year after the transition process there was a significant decrease in HbA1c levels in group B, while a trend towards an increase was observed in group A, three years after the transition process similar levels were observed in both groups.</p> <p>Three years after the transition to ADS, there was a significant reduction in the clinical attendance in group A than in group B, despite a similar compliance in the last year in PDS care (57 +/- 5.0 vs. 80 +/- 12.5%, <math>p &lt; 0.05</math>).</p>
Service delivery, organisational outcomes. <i>List outcomes</i>	<i>Clinic attendance rate in ADS</i>
<i>Whose perspective? List whose views, if any, are reported (e.g. patients, parents, caregivers)</i>	patients
Costs/economic matters <i>State whether paper contains any economic info.</i>	<i>none</i>
Key process issues - Barriers	n/a
Key process issues – facilitating factors	n/a
Key issues for young people	n/a
Recommendations for successful transition	A better result after structural transition was indicated. They speculate that the sense of liability for young people could be improved by sharing the process with a group of young people, presenting the transition as a goal and putting the patient in the middle of the process with a sidelong role of the family. In addition the insurance of a continuative assistance through all of the process and the possibility to come back may decrease the stress of the transition. The continuous medical and nursing care during the planned transition could play a role in the favourable opinion of young patients.
Any negative impacts reported? <i>Yes/ No Individual/ organisational etc.</i>	In group B one patient refused the transition and another returned to PDS soon after the first visit in ADS. Also in group B, one patient had a hypoglycaemic crisis and was hospitalised in ADS; no other side effects were reported during transition.
Limitations/weaknesses of study <i>As reported by authors</i>	Cautions needed in considering results and implication that a better clinic attendance rate results after a structured transition instead of a structured one, because the visits were much more frequent in PDS than in ADS. Timing of clinical and biochemical examinations were also different. A confounding bias may carry on from the different periods that they retrospectively investigated from 1994 to 1999 for the unstructured transition and from 2000 to 2004 for the structured one, even if the reference physicians were the same for all the

	period.
Any other comments	Some issues with language/ translation.

<b>Clarizia et al 2009. Transition to adult health care for adolescents and young adults with congenital heart disease: perspectives of the patient, parent and health care provider, <i>Can J Cardiol</i>, 25 (9), e317- e322.</b>	
Country: Canada	
Relevant to review questions: 2	
Study design: Qualitative data collection, quantitative analysis methods	
Method of data collection <i>e.g. 15 Semi structured interviews &amp; 2 focus groups</i>	Semi-structured interviews (15-25 minutes) with 23 patients aged 9 – 18 years old with congenital heart defects and 22 parents of these patients. A self administered questionnaire was completed by 45 health care providers- including 21 paediatric cardiologists, 19 nurses and 5 allied health professionals (dietitians/social workers/occupational therapists/ child-life therapists).
<b>INTERVENTION</b>	
Name/ nature of model (if described)	Examined the attitudes and opinions regarding transition and its necessary preparation from the perspectives of patients, their parents and health care providers in a paediatric cardiology outpatient clinic No formal transition programme was in place at the time.
Theoretical model (if given)	None reported
Condition <i>e.g. diabetes</i>	Congenital Heart disease
Comparator?	None
Setting	A paediatric cardiology outpatient clinic at The Hospital for Sick Children (Toronto, Ontario)
Who delivered it?	n/a
<b>POPULATION</b>	
Target recipients ( <i>who it was aimed at</i> ) <i>e.g. age, sex, health condition</i>	A sample of consecutive patients aged 9-18 years with congenital heart defects and their parent(s). The sample had presented for regular follow up in the paediatric cardiology outpatient clinic over a 6 week period Patients with developmental delay or disability were excluded.
Individual outcomes <i>List outcomes, how each was measured (e.g. scale), who measured it and when it was measured</i>	Patient interview: Patients’ knowledge about their diagnosis, medication, antibiotic prophylaxis, lifestyle issues, transition and what topics the patient wished to receive more information about at his or her routine clinic visits.  Parent interview: Knowledge of and concerns about the transition process, and whether they perceived their child to be ready for transition. Extent of involvement of the parent(s) in their child’s care and what the parents believed about their roles and the roles of their child, nurses and physicians in preparing their child for transition.  Health Care Provider survey Opinions and attitudes about the state of transition preparation in the outpatient clinic, what they perceived as barriers to successfully transitioning their patients, what they currently do to prepare them and what they felt was necessary to prepare their patients more effectively.
Clinical/health outcomes	The majority of patients had a basic knowledge of their heart conditions, only a third had a clear understanding of the implications and changes associated with their future transition to adult care. Nearly half expressed a desire for more information about their heart condition.  Most parents were aware that their child would transition to adult care, nearly half had some concerns about transition and half felt their child was ready. Parents’ involvement was extensive, with nearly all accompanying their child to medical appointments, two thirds staying with them for the entire visit and

	<p>nearly half administering their medication. Most parents felt the institution was preparing their child for transition.</p> <p>Providers felt that currently children were not sufficiently prepared for transition. The majority thought that children should start learning about transition between the ages of 13 and 16. Physicians were more involved in teaching about diagnosis and symptoms than nurses.</p>
Service delivery, organisational outcomes. <i>List outcomes</i>	None.
<i>Whose perspective? List whose views, if any, are reported (e.g. patients, parents, caregivers)</i>	Patients, their respective parent(s) and health care providers
Costs/economic matters <i>State whether paper contains any economic info.</i>	None
Key process issues - Barriers	<p>Parents who took responsibility for all or most of their child's care activities appeared to impede development of confidence and independence by not allowing their children the opportunity to take an active role in their own care. Parents who assumed responsibility for most/all of their child's care had children who were unsure of their diagnosis and did not communicate directly with their providers. Alternatively, the child may lack the confidence to be self-advocating about their health and thus parents feel obliged to take over certain aspects of their care.</p> <p>The paediatric cardiologists may be enabling this type of parental involvement because they do not feel as though parents are obstacles to transition preparation.</p>
Key process issues – facilitating factors	<p>Patients who were more knowledgeable about their heart condition were more likely to respond to providers' questions themselves and had more understanding of the implications of transition to adult care.</p> <p>Patients who were able to explain their diagnosis in both lay and medical terms appeared to be more confident. They communicated directly with providers instead of using their parents as a proxy and were self-assured in their ability to take care of themselves.</p> <p>Parents of children who were generally confident and knowledgeable about their child's diagnosis tended to encourage their child's independence by letting them see providers alone and encouraging them to take an active role in their care.</p>
Key issues for young people	None reported
Recommendations for successful transition	<p>A concerted effort must be made to implement a formalised transition process as part of the regular routine of the outpatient clinic visit.</p> <p>The delegation of explicit responsibilities and a clear definition of roles for each participant (including parents) are needed.</p> <p>There is a demonstrable need for consistent and thorough developmentally appropriate education for patients with CHD, ideally this education should begin as early as possible.</p>

	<p>At the time of the transition, care in the paediatric setting must adapt to accommodate the presence of an additional adult (the patient) who needs to be treated independently of the family structure.</p> <p>A patient who is able to establish a relationship with his/her physician in the paediatric setting will have more confidence to do the same with a new adult provider- both the paediatric physician and the patient need to strive for this. Devoting a portion of the visit to seeing the patient without his/her parents present is a gentle push that obliges the young adult to be a self-advocate of his/her health and also encourages the parent to begin a lesser role in his/her child's care. It is also an opportune time to teach about diagnoses and discuss the imperative of regular care.</p>
Any negative impacts reported? Yes/ No <i>Individual/ organisational etc.</i>	Providers who reported that the cardiac program was currently not preparing their children for transition felt that the lack of a formal transition program was an important problem (90%)
Limitations/weaknesses of study <i>As reported by authors</i>	Limited by its sample because only eligible patients who had time to participate were enrolled. This excluded a number of eligible participants whose participation was unfeasible from a time perspective. The study is somewhat limited by its small sample size.
Any other comments	The results are unadjusted for the child's age – this is a serious flaw as the range of 9-18 years is very wide developmentally, and one would expect more parental involvement and a less independent child at age 9 than at age 18. This could account for all the findings related to parents with more involvement having less independent children!

<b>de Beaufort C, Jarosz-Chobot P, Frank M, de Bart J, Deja G Transition from pediatric to adult diabetes care: smooth to slippery? Pediatric Diabetes 2010: 11: 24-27.</b>	
Country: 36 countries, all members of ISPAD.	
Relevant to review questions: 1, 3	
Study design: 21-item questionnaire. Quantitative.	
Method of data collection <i>e.g. 15 Semi structured interviews &amp; 2 focus groups</i>	21-item questionnaire sent by email to all members of ISPAD (578) along with an explanatory letter. At the time of mailing, members comprised those interested in childhood diabetes (approx. 2/3rds physicians and the remainder other HCPs, e.g. nurses, psychologists and dietitians). Survey resent to membership 4 months later to increase response rate. 92 questionnaires (16%) from members representing 36 countries were included in the analysis.
<b>INTERVENTION</b>	
Description of model/ intervention	Collect data about practices of pediatric diabetes HCPs in different parts of world concerning transition from pediatric to adult diabetes care.
Theoretical model (if given)	Not stated.
Condition <i>e.g. diabetes</i>	T1DM.
Comparator?	No
Setting	Various settings where transition of youth with T1DM takes place.
Who delivered it?	Not stated.
Description of model/ intervention	See above.
<b>POPULATION</b>	
Target recipients ( <i>who it was</i>	HCPs of various disciplines working in the transition of youth with

<i>aimed at) e.g. age, sex, health condition</i>	T1DM.
Outcomes for individuals: <i>List outcomes, how each was measured (e.g. scale), who measured it and when it was measured.</i>	21-item questionnaire. Health discipline of those completing questionnaire, setting in which they work, age range of patients followed up in the centre, type of physician specialist most often responsible for caring for adolescent in centre.  Transition process, e.g. where and at what age youth are transferred to adult care, who initiates referral, how formalised is the process, how many youth make a successful transition, etc.?  Opinions of participants regarding ideal age for transition and suggestions for improving transition process.
Clinical/ health outcomes	
Service delivery, organisational outcomes. <i>List outcomes</i>	63.7% from university hospitals, 27.4% regional hospitals, 4.4% in national centres/district hospitals and 4.4% in private hospitals. In 76% of the centres youth are seen until age of 18 years. 36% of pediatric centres see adults over 25 years. Most children under 12 (87%) are followed by pediatric diabetologist. Half of centres reported a structured transition programme targeting youth aged 16-25 years.
<i>Whose perspective? List whose views, if any, are reported (e.g. patients, parents, caregivers)</i>	HCPs. 92 members representing 16% of ISPAD membership from 36 countries. 88 = physicians and 4 = nurses.
Costs/economic matters <i>State whether paper contains any economic info.</i>	Not stated.
Key process issues - Barriers	Despite increased awareness of need to improve transitional care, most pediatric centres lack a structured programme to promote smooth, systematic transition to adult diabetes care. Where programmes do exist they occur at local level and are limited to informal, personal contact between centres.
Key process issues – facilitating factors	In general, transition is initiated by pediatric unit. Different processes of transition described, including phone contact, letter, joint clinics either at pediatric or adult site, cross-over meetings with pediatric and adult team and group transfer.
Key issues for young people	Not reported.
Recommendations for successful transition	An evaluation of successful transfer to adult care is done in 35% of centres. Larger centres generally reported using more than one method to promote successful transition. 90% of those who responded recommended transition planning begin at least 1 year prior to transfer.  Responders suggested a number of strategies to improve transition to adult care, including: Early joint clinics, A MDT approach to transition,

	<p>An early and gradual promotion of personal responsibility for self-management including parents etc where appropriate.</p> <p>Increased inclusion of youth in the planning of their future health care.</p> <p>Transition should be long, planned process and referral should be accompanied by a written summary of the pediatric experience and medical situation.</p> <p>Structured transition and monitoring of its effects are necessary if drop-out rates are to be reduced and complications prevented.</p> <p>Critical that increased efforts to optimise control in youth not followed by rapid deterioration in young adulthood because of lack of thoughtful transitional care.</p>
<p>Any negative impacts reported? Yes/ No Individual/ organisational etc.</p>	<p>Evaluation reported to be rare or not done at all by 60% of those surveyed.</p>
<p>Limitations/weaknesses of study As reported by authors</p>	<p>Limited sample and sample size, therefore, information should be interpreted with caution. Most responders were physicians and those who did respond may be those for whom transition is a particular passion or problem.</p>
<p>Any other comments</p>	

<p><b>Fernandes SM, Fishman L, O’Sullivan-Oliveira J et al. Current practices for the transition and transfer of patients with a wide spectrum of pediatric-onset chronic diseases: Results of a clinician survey at a free-standing pediatric hospital. Int J Child and Adolescent health 2010; 3 (4S): 507 - 515</b></p>	
<p>Country: USA</p>	
<p>Relevant to review questions: 1 and 3</p>	
<p>Study design: survey</p>	
<p>Method of data collection e.g. 15 Semi structured interviews &amp; 2 focus groups</p>	<p>Web-based multiple choice cross-sectional survey randomly distributed to 479 outpatient clinicians.</p>
<p><b>INTERVENTION</b></p>	
<p>Description of model/ intervention</p>	<p>The study examines healthcare professionals’ perceptions of the spectrum of transition and transfer practices across a broad spectrum of disorders.</p>
<p>Theoretical model (if given)</p>	<p>Not given.</p>
<p>Condition e.g. diabetes</p>	<p>“a wide range” of disorders, actual disorders not reported.</p>
<p>Comparator?</p>	<p>All transition and transfer practices of those included in the survey are compared.</p>
<p>Setting</p>	<p>Hospital outpatient clinicians were surveyed.</p>
<p>Who delivered it?</p>	<p>Not reported.</p>
<p><b>POPULATION</b></p>	
<p>Target recipients (who it was aimed at) e.g. age, sex, health condition</p>	<p>The survey was aimed at health care clinicians at Children’s Hospital Boston (CHB) a 396 bed tertiary care pediatric hospital. A randomised sample of physicians, nurse practitioners and nurses who were likely to provide care to patients over the age of 11 years in the outpatients setting were selected. In addition, all social workers and physician assistants were sent the survey.</p>
<p>Outcomes for individuals: List outcomes, how each was measured (e.g. scale), who measured it and when it was measured.</p>	<p>The final survey included a list of 25 questions within the following six categories:</p> <ol style="list-style-type: none"> <li>1. Inclusion criteria</li> <li>2. Self-management (transitioning) skills assessment and education</li> <li>3. Transfer to an adult-orientated health care system</li> </ol>



	<p>4. Demographics</p> <p>5. Age-appropriate care</p> <p>6. resources</p>
Clinical/ health outcomes	
<p>Service delivery, organisational outcomes.</p> <p><i>List outcomes</i></p>	<p>73% of clinicians stated their patients received transitioning (self management) skills assessment/ education. The majority (58%) indicated that such skills assessment is provided by the clinician and other members of their team. 92% indicated that transitioning (self management) skills assessment and education were usually provided in an informal fashion. Most providers stated they begin their transitioning assessment starting in mid adolescence.</p> <p>Age appropriate care: 98% of clinicians reported that they could provide age-appropriate care to patients under the age of 18 but only 43% reported that they could provide age-appropriate care to patients &gt;25 years.</p> <p>Resources for transition and transfer: 64% of clinicians felt there should be a specific programme within their department to provide education and assessment of transitioning (self management) skills. The majority of clinicians thought their institution should provide resources for the development of such programmes. 95% of clinicians were in agreement that there should be a process to streamline the transfer of patients to an adult oriented healthcare system.</p>
<p><i>Whose perspective?</i></p> <p><i>List whose views, if any, are reported (e.g. patients, parents, caregivers)</i></p>	Healthcare professionals: physicians, nurse practitioners, nurses, social workers and physician assistants.
<p>Costs/economic matters</p> <p><i>State whether paper contains any economic info.</i></p>	No.
Key process issues - Barriers	Clinicians tended to agree on barriers to transition, which were: parent's emotional attachment to the institution (96%), patient and parent emotional attachment to the provider (each 95%), patient's emotional attachment to the institution (93%), patient's emotional/ cognitive delay (86%), provider's attachment to the family (79%).
Key process issues – facilitating factors	The most common patient characteristics endorsed by physicians as reasons to transfer a patient to an adult oriented healthcare system were age (79%), presence of adult co-morbidities (78%), graduation from college (67%), pregnancy (58%) and marriage (56%). The use of alcohol or illicit drugs (29%) and graduation from high school (16%) were less likely to prompt transfer.
Key issues for young people	Not reported.
Recommendations for successful transition	Not stated.
<p>Any negative impacts reported?</p> <p><i>Yes/ No</i></p> <p><i>Individual/ organisational etc.</i></p>	No.
Limitations/weaknesses of study	Single centre study, may not allow for generalisability to other institutions. Self reported results may overestimate the %of clinicians

As reported by authors	who perform transitioning (self management) education and assessment, due to social desirability bias.
Any other comments	

<b>Gilliam P. Transitional care for adolescents with HIV: characteristics and current practices of the Adolescent Trials Network systems of care. 2009. Graduate School Theses and Dissertations.</b>	
Country: USA	
Relevant to review questions: 1	
Study design: Qualitative	
Method of data collection <i>e.g. 15 Semi structured interviews &amp; 2 focus groups</i>	Semi-structured interviews with 19 key informants, and review of clinic documents.
<b>INTERVENTION</b>	
Description of model/ intervention	Not given.
Theoretical model (if given)	Not given.
Condition <i>e.g. diabetes</i>	HIV
Comparator?	None.
Setting	Health care providers affiliated with the Adolescent Trials Network of HIV/ AIDS interventions
Who delivered it?	Not reported.
<b>POPULATION</b>	
Target recipients ( <i>who it was aimed at</i> ) <i>e.g. age, sex, health condition</i>	The population of interest is HIV-infected adolescents who are transitioning or will be transitioning from a child-centred health care environment to an adult-centred care environment.  Interviews were conducted with 19 staff members: 7 social workers, 7 nurse practitioners, 3 physicians, 1 registered nurse, 1 health educator from 14 ATN clinics.
Outcomes for individuals: <i>List outcomes, how each was measured (e.g. scale), who measured it and when it was measured.</i>	Research question one: How do ATN health care team members view transition?  Research question two: What do ATN health care team members perceive as facilitators to a successful transition to adult care?  Research question three: What do ATN health care team members perceive as barriers to a successful transition to adult care?  Research question four: what are the similarities and differences among the clinics that have a structured transition program and those that do not?  Research question five: What strategies have ATN systems of care developed to assist patients in making a successful transition to adult medical care?
Clinical/ health outcomes	<i>n/a</i>
Service delivery, organisational outcomes. <i>List outcomes</i>	<i>(from Discussion)</i>  <i>Research question one: How do ATN health care team members view transition?</i>  All the key informants agreed that staff members shared similar views of transition. When describing these similar views, words such

	<p>as teamwork, collaborative and multidisciplinary were frequently used. The key informants from the six clinics that incorporated a structured transition process provided a much more comprehensive and detailed view of transition. Proposed foundations for a structured transition program are:</p> <ul style="list-style-type: none"> <li>• Application of adolescent development theory</li> <li>• Consideration of developmental age together with chronological age</li> <li>• Early initiation of transition planning (ages 14 to 16) or when admitted to adolescent care clinic</li> <li>• Gradual transition process</li> <li>• Individualisation of the transition plan</li> <li>• Use of a holistic approach to medical and psychosocial needs</li> <li>• Planned learning activities during transition to enhance the adolescent’s sense of autonomy, personal responsibility and independence</li> <li>• Care provided by culturally competent staff</li> </ul> <p><i>Research question four: What are the similarities and differences among the clinics that have a structured transition program and those that do not?</i></p> <p>The key informants from the clinics with the most comprehensive transition plans stressed the need to use a developmental approach to plan an individualised transition experience. Clinics that used structured transition program viewed transition as a process that occurs over time, rather than an event or the actual transfer of care.</p> <p><i>Research question five: What strategies have ATN systems of care developed to assist patients in making a successful transition to adult care?</i></p> <p>The six clinics that have a structured transition program include introductions or gradual exposure of the adolescent to their adult provider and a tour of the potential adult clinics during the transition process. Continued contact between adolescent and their case manager during first year after transfer to adult clinic.</p> <p>Two salient themes were identified that did not relate to any of the research questions:</p> <ul style="list-style-type: none"> <li>• Special consideration during transition for adolescents with cognitive or developmental delays</li> <li>• Pregnant adolescent females experienced a smoother and more successful transition to adult care</li> </ul>
<p><i>Whose perspective? List whose views, if any, are reported (e.g. patients, parents, caregivers)</i></p>	<p>Health care providers.</p>
<p><i>Costs/economic matters State whether paper contains any economic info.</i></p>	<p>No</p>
<p>Key process issues - Barriers</p>	<p><i>Research question three: What do ATN health care team members perceive as barriers to a successful transition to adult care?</i></p> <p>Lack of confidentiality, “AIDS clinics”, drug abuse, mental health issues, sadness at loss of long-standing therapeutic relationships (from patients and providers), funding issues.</p>

Key process issues – facilitating factors	<p><i>Research question two: What do ATN health care team members perceive as facilitators to a successful transition to adult care?</i></p> <p>Intrinsic characteristics included emotional maturity and the ability and motivation to function independently. External factors included a strong social support system, uninterrupted health insurance benefits, available transportation system and stable housing. Characteristics of adult clinics associated with successful transition are:</p> <ul style="list-style-type: none"> <li>• A single contact person assists the adolescent in transition</li> <li>• The new provider is introduced to the adolescent at the start of the transition process</li> <li>• Comprehensive services are provided including primary care, pharmacy and dental services</li> <li>• Psychosocial services such as case management, mental health and support groups are provided</li> <li>• Flexibility is provided as the adolescent adjusts to the adult clinic environment</li> <li>• The staff are culturally competent and LGBT friendly</li> <li>• Follow-up is facilitated by the case manager from the pediatric clinic</li> <li>• Adult providers deliver age and developmentally appropriate care for the adolescent</li> <li>• Communication between providers from the adolescent and adult sites is shared and timely</li> </ul>
Key issues for young people	Not reported.
Recommendations for successful transition	Not reported
Any negative impacts reported? <i>Yes/ No Individual/ organisational etc.</i>	no
Limitations/weaknesses of study <i>As reported by authors</i>	Potential limitations included researcher bias, a social desirability bias in the key informants and a lack of generalizability.
Any other comments	

<b>Irvine T, Srinivasan R, Casson DH et al. Assessing the value of a pre-transfer meeting in IBD transition services. <i>Gastrointestinal Nursing</i> 2010; 8 (7): 19-25</b>	
Country: UK	
Relevant to review questions: 1, 3	
Study design: cross-sectional survey	
Method of data collection <i>e.g. 15 Semi structured interviews &amp; 2 focus groups</i>	Semi-structured postal questionnaire given to 66 families (35 responded).
<b>INTERVENTION</b>	
Description of model/ intervention	<p>Structured approach:</p> <ul style="list-style-type: none"> <li>• To introduce the concept of transition by age 13-14 years</li> <li>• To time transition as per individual patient needs</li> <li>• A 'pre-handover' meeting at the paediatric hospital for the families to meet the new adult team with the paediatric team present. This meeting is an open forum and an opportunity for individual case discussion, queries and</li> </ul>

	<p>support before transfer.</p> <ul style="list-style-type: none"> <li>• A comprehensive clinical summary from the paediatric hospital to the adult hospital before transfer</li> <li>• First hospital appointment at the adult centre with the paediatric team in the clinic room providing an interactive handover</li> <li>• Handover to adult services at the end of the clinic appointment</li> <li>• Continued support as desired in individual instances.</li> </ul> <p>General approach: transfer young people after their GCSE exams, once they are 16 years and older. Transition arrangements have been established with the adult hospital. Topics discussed at a pre-handover meeting held with all families include: young people being in the driving seat concerning all decision making; similarity of therapeutic approach between adult and paediatric practices; the fact that parents will not be able to stay overnight during inpatient admissions; appointments and clinic systems; telephone access to nurse specialists; differences in treatment practices; less choice with blood sampling; enteral feed regimen differences for Crohn's disease; research and experimental treatment differences.</p> <p>The pre-transfer meeting is held one month before the handover clinic and lasts one hour. It is a group discussion led by an adult gastroenterologist, nurse specialist and dietician. At the end of the session there is an opportunity to talk informally with members of the team.</p>
Theoretical model (if given)	None given.
Condition <i>e.g. diabetes</i>	Inflammatory bowel disease (IBD)
Comparator?	None
Setting	Transition between paediatric services at Alder Hey Children's NHS Foundation Trust, Liverpool and the Royal Liverpool University Hospital (adult centre).
Who delivered it?	Introduction by paediatric gastroenterologist, the led by adult gastroenterologist, nurse specialist and dietician.
<b>POPULATION</b>	
Target recipients ( <i>who it was aimed at</i> ) <i>e.g. age, sex, health condition</i>	Young people (adolescents) who had been through the transition process between Alder Hey and RLUH from 2003 – 2008. 66 families were contacted, 35 returned the questionnaire (53% response rate).
Outcomes for individuals: <i>List outcomes, how each was measured (e.g. scale), who measured it and when it was measured.</i>	<p>Patient information:</p> <ul style="list-style-type: none"> <li>• Did you attend the pre-transfer meeting? (Yes/ No)</li> <li>• Did you have enough information regarding the move to the adult hospital? (4 point ordinal scale)</li> <li>• Do you think you had the opportunity to discuss any changes as a result of transition to adult services at the pre-transfer meeting? (Yes/ No/ Don't know)</li> <li>• Do you feel the pre-transfer meeting increased or reduced your anxieties about your transfer? (3 point ordinal scale/ do not recall)</li> </ul> <p>Patient satisfaction:</p> <ul style="list-style-type: none"> <li>• How satisfied were you about meeting the adult team prior to seeing them at the handover clinic? (4 point ordinal scale)</li> <li>• Were the right people present at your first clinic</li> </ul>

	<p>appointment at the adult hospital? (Yes/ No)</p> <ul style="list-style-type: none"> <li>How helpful was it to you that members of the paediatric team were at your first clinic appointment? (3 point ordinal scale)</li> </ul> <p>Suggestions:</p> <ul style="list-style-type: none"> <li>Do you feel there should have been others involved in your care present? (Yes/ No/ Don't know)</li> <li>Subjective comments.</li> </ul>
Clinical/ health outcomes	<p>33/ 35 were satisfied or very satisfied with meeting the adult team prior to seeing them at the handover clinic (p&lt;0.0001)</p> <p>31/ 35 felt they were given enough information about the move (p&lt;0.0001)</p> <p>30/ 35 felt they had opportunity to discuss change (p&lt;0.0001)</p> <p>22/ 35 felt the pre-transfer meeting reduced their anxiety about transfer (p&lt;0.0877)</p> <p>31/35 felt the right people were present at the first adult appointment (p&lt;0.0001)</p> <p>32/ 35 found it fairly or very helpful to have members of the paediatric team at the first adult appointment (p&lt;0.0001)</p> <p>Suggestions for future transition: GPs and dietitians should form a part of the transition process. Creation of an email forum for young people to make contact and share information and experiences.</p>
Service delivery, organisational outcomes. <i>List outcomes</i>	<i>None reported.</i>
<i>Whose perspective? List whose views, if any, are reported (e.g. patients, parents, caregivers)</i>	Patients and carers.
Costs/economic matters <i>State whether paper contains any economic info.</i>	<i>No.</i>
Key process issues - Barriers	None reported.
Key process issues – facilitating factors	None reported.
Key issues for young people	Provision of adequate information Opportunity to discuss change Reduction in perceived anxiety about the transfer
Recommendations for successful transition	Pre-transfer meeting, facilitating an opportunity to meet the adult team before the first clinic visit, and offering families the opportunity to meet other families with the same condition.
Any negative impacts reported? <i>Yes/ No Individual/ organisational etc.</i>	No – although it increased anxiety for a few.
Limitations/weaknesses of study <i>As reported by authors</i>	Questionnaire not validated. Response rate of 53%; no drop out analysis was undertaken. Potential 'Hawthorne effect': patients and carers may have been pleased to receive attention from researchers.

Any other comments	
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**Michaelis, A (2009) Helping young adults succeed in a world where “You Can’t”: Transitions to healthy adulthood for HIV-positive youths in Baltimore, Maryland. PhD thesis.**

Country: America (Baltimore, Maryland)

Relevant to review questions: 1, 2 & 3

Study design: Qualitative methodology

Method of data collection <i>e.g. 15 Semi structured interviews &amp; 2 focus groups</i>	Ethnographic interviews with young adults infected with HIV at birth, without cognitive impairments that would prevent consent.  Semi-structured, in-depth interviews with clinic staff at the collaborating pediatric clinic, at the collaborating adult HIV clinic and with clinic staff responsible for directing the transition programmes at a small sample of other pediatric and adolescent HIV clinics around the country, who had substantial experience developing and implementing transition programmes - “transition leaders”.  47 individuals: 15 perinatally HIV infected youths receiving care at pediatric HIV clinic in Baltimore; 14 staff members at the pediatric clinic; 11 staff members at an adult HIV clinic in Baltimore and 7– individuals with at other HIV clinics around the United States.
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**INTERVENTION**

Description of model/ intervention	Qualitative interviews to explore facilitators and barriers to successful transition from pediatric to adult medical care for those youths living with HIV. Participants = those who are in receipt of pediatric care and, therefore, not yet begun the transition process to adult care.
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Theoretical model (if given)	Theories of Life Course Health Development, risk and resilience, social capital and coping form the basis of a conceptual framework built iteratively throughout the research.
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Condition <i>e.g. diabetes</i>	HIV.
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Comparator?	No.
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Setting	HIV infected youth: pediatric and adult HIV clinics in Baltimore, Maryland or by phone in the recipients home. Staff members: staff offices or telephone for those in areas further afield.
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Who delivered it?	PhD student.
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Description of model/ intervention	See above.
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**POPULATION**

Target recipients ( <i>who it was aimed at</i> ) <i>e.g. age, sex, health condition</i>	HIV infected youth aged 18-24: 37 individuals (21 females and 16 males) were eligible; final sample = 15 (8 women; 7 men). Exclusively African American sample reflective of the clinic population. Socioeconomic status: high (n=5); moderate (n=6); low (n=4).  Staff at pediatric clinic: 14 (2 nurse practitioners, 2 physicians,
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	<p>2 social workers, 2 nurse case managers, clinic’s psychiatrist, child life specialist, outreach coordinator, home visit specialist, youth advocate and one adolescent fellow).</p> <p>Staff at adult clinic: 11 (3 physicians, 1 infectious disease fellow, 1 adult/pediatric fellow, social work coordinator, 2 additional social workers, 1 nurse case manager, 1 patient advocate and the clinic manager.</p> <p>For the “transition leaders” a snowball sample procedure was adopted. 7 represented clinics in Baltimore, Washington DC, New York City (2 clinics), Miami (2 clinics) and Los Angeles.</p>
<p>Outcomes for individuals: <i>List outcomes, how each was measured (e.g. scale), who measured it and when it was measured.</i></p>	<p>Youths’ experiences and self-perceived needs related to transitions from adolescence to adulthood and related to transitional medical care.</p> <p>Attitudes and practices of pediatric and adult medical providers specialising in HIV care in relation to transitioning patients.</p> <p>Types of clinic-based intervention strategies that are useful for facilitating successful transitions.</p> <p>The barriers to successful transition from pediatric to adult medical care for youths living with HIV.</p>
<p>Clinical/ health outcomes</p>	<p>No.</p>
<p>Service delivery, organisational outcomes. <i>List outcomes</i></p>	<p>Successful transition clinics’ common outcomes:</p> <ol style="list-style-type: none"> <li>1. Transition is discussed frequently with patients starting in early teenage years; skill-building in preparation for adult care occurs regularly during medical and social work appointments.</li> <li>2. During year prior to transition clinic begins more intensive preparations for adult care, including orientation visits to adult clinics accompanied by staff member from pediatric clinic.</li> <li>3. Transition to adult care typically occurs shortly before a patient reaches 25 years. Clinics found youth were unprepared for adult care at earlier ages.</li> <li>4. Closer collaboration of pediatric and adult clinic staff.</li> </ol>
<p><i>Whose perspective? List whose views, if any, are reported (e.g. patients, parents, caregivers)</i></p>	<p>See ‘target recipients’ above.</p>
<p>Costs/economic matters <i>State whether paper contains any economic info.</i></p>	<p>No.</p>
<p>Key process issues - Barriers</p>	<p><b>See page 173 and 174 for a table outlining the barriers to successful transition and recommended clinic-based interventions.</b></p> <p>Life skills deficit cited as primary threat to youths’ transition/feeling unprepared to step-up to tasks expected of them as young adults.</p>



	<p>Negative impressions of adult clinic environment.</p> <p>Adapting to role change from passive to proactive health consumer represents one of the central challenges for youths transitioning from pediatric to adult care.</p> <p>Structural and cultural differences between pediatric and adult clinics. Lower case loads of pediatric staff means more time for individual patients and greater flexibility than for patients in adult service.</p> <p>Planning issues: pediatric clinics have no formal procedures, guidelines or timelines structuring the transition process. Individual providers each have their own methods.</p> <p>Lack of systematic communication between pediatric and adult clinics. Misinformation/inadequate information hinders the transition process. Also, lack of communication between pediatric clinic and other adult care institutions in the community.</p>
Key process issues – facilitating factors	<p><b>See service delivery outcomes above.</b></p> <p>Strong interpersonal relationships with clinic staff.</p> <p>Devise strategies for maintaining mutually beneficial clinic-patient relationships even after youths leave pediatric care, e.g. keep former patients involved by making them members of the clinic’s community advisory board, enlisting them as mentors to younger patients (peer support), etc.</p>
Key issues for young people	See other sections.
Recommendations for successful transition	<p>Improving youths’ emotional readiness and skills for adult medical care, e.g. life skills workshops provided in clinics.</p> <p>Creating new transition policy and programming that is explicit and formalised, and which utilises timelines that are tied to individual patients’ developmental stages rather than a rigid schedule. The key to success is to have gradual and individualised plans. Written plans increase the accountability of patients and providers in achieving transition goals.</p> <p>Providing adequate transition preparation time.</p> <p>Cross-clinic coordination: enhancing collaboration between pediatric and adult clinics.</p> <p>Post-transfer planning and monitoring: 1. Strategies to make the pediatric clinic’s withdrawal of support more gradual for patients, 2. Monitoring and evaluation of patient outcomes after transition.</p>

	<p>Transition process is improved when support is provided by pediatric clinic to youths for 6-12 months after they make transition to adult care.</p> <p>Critical to have a policy in place for those youths who fail to make a successful transition.</p> <p><b>Lots of detail provided in relation to how to improve communication between pediatric and adult services – see page 161.</b></p> <p>For example, location of two clinics within the same hospital, assigning specific staff member at pediatric clinic to coordinate transition process, develop streamlined process for condensing patients' histories into concise summary sheets, etc.</p>
<p>Any negative impacts reported? <i>Yes/ No</i> <i>Individual/ organisational etc.</i></p>	<p>Because pediatric clinic staff members are some of main providers of "family" support, the transition away from pediatric care has the potential to undermine the core of many youths' social support networks.</p>
<p>Limitations/weaknesses of study <i>As reported by authors</i></p>	<p>Lack of population generalizability. Sampling criteria: study only includes those perinatally infected youth; transition leaders represents only one perspective of their clinic's transition programmes; small sample of pediatric and adult clinic staff members; study's reliance on perspectives of youths not yet begun transition process and on clinic staff members who had no experience implementing a transition programme; researcher's perspective, reliance on study participant's representations of their experiences.</p>
<p>Any other comments</p>	<p>Very comprehensive study.</p>

<p><b>Valenzuela JM, Buchanan CL, Radcliffe J et al. Transition to adult services among behaviourally infected adolescents with HIV – a qualitative study. Journal of Pediatric Psychology 2011; 36 (2): 134-140</b></p>	
<p>Country: USA</p>	
<p>Relevant to review questions: 3</p>	
<p>Study design: Qualitative study</p>	
<p>Method of data collection <i>e.g. 15 Semi structured interviews &amp; 2 focus groups</i></p>	<p>Semi-structured interviews conducted with 10 young adults ranging from 24 to 29 years old. Themes were derived from coding participant interviews.</p>
<p><b>INTERVENTION</b></p>	
<p>Description of model/ intervention</p>	<p>All participants had previously been treated at the same HIV clinic in a pediatric hospital with interdisciplinary primary and HIV speciality care for adolescents. A team of physicians, nurse practitioners, nurses, social workers and mental health professionals provided comprehensive care for HIV-positive youth, including individualised transition preparation.</p>
<p>Theoretical model (if given)</p>	<p>Not given.</p>
<p>Condition</p>	<p>Behaviourally acquired HIV.</p>

<i>e.g. diabetes</i>	
Comparator?	None.
Setting	Multiple adult care settings including hospital-based and community practice-based settings, with care from nurse practitioners and HIV physician specialists.
Who delivered it?	A team of physicians, nurse practitioners, nurses, social workers and mental health professionals.
<b>POPULATION</b>	
Target recipients ( <i>who it was aimed at</i> ) <i>e.g. age, sex, health condition</i>	<p>Study inclusion criteria for participants were: older than 18 years, previously treated at the adolescent clinic for at least 1 year within the prior 5 years, now receiving HIV care by an adult health-care provider and available by telephone. Those with perinatally acquired HIV and/ or with cognitive or health difficulties were excluded.</p> <p>The 10 included participants were aged 24 – 29 years, seven were female. Seven were African-American, two Caucasian and one biracial. Age at diagnosis ranged from 14.9 years to 21.5 years. Time since transition ranged from 2 months to 5 years. Age at transition ranged from 24 to 27 years. Length of time treated by adolescent care providers ranged from 2 years to 11 years.</p>
Outcomes for individuals: <i>List outcomes, how each was measured (e.g. scale), who measured it and when it was measured.</i>	<p>60 minute semi structured interviews were conducted in a private room and included the following questions:</p> <ol style="list-style-type: none"> <li>1. How does your adult HIV care experience compare to your previous pediatric experience?</li> <li>2. What helped you during your transition?</li> <li>3. What are some things that have made it harder to transition from pediatric to adult HIV care?</li> <li>4. What changes would you like to see in place in order to create the ideal transition experience for other young adults with HIV?</li> </ol>
Clinical/ health outcomes	Not reported (see key issues for young people)
Service delivery, organisational outcomes. <i>List outcomes</i>	<p><b>Theme 4: Recommendations for improving the transition process.</b> Participants recommended early communication and preparation for transition, options and control in the process and assistance with coordination and linking of services.</p> <p>Adult care  <b>Theme 5: a significant change in the experience of care.</b> Descriptions of adult care centred on differences in both the health care setting and the health care system. Young adults described increased concerns related to dealing more independently with insurance requirements, longer waits and/ or less time with providers.</p>
<i>Whose perspective? List whose views, if any, are reported (e.g. patients, parents, caregivers)</i>	Patients.
Costs/economic matters <i>State whether paper contains any economic info.</i>	No.
Key process issues - Barriers	Insurance referral system; relationship with adult provider; adult clinics displaying indications of infectious disease care; childcare

	issues.
Key process issues – facilitating factors	See ‘recommendations’?
Key issues for young people	<p>Six broad themes emerged, two in each phase of experience.</p> <p>Adolescent Care  <b>Theme 1: Providers as family.</b> Almost all participants indicated a strong relationship with the adolescent care team. Strong feelings were particularly evident among participants who had disclosed their status to few of their family and friends. Several participants indicated that they developed trust or faith in adolescent team members over time and some continued to communicate with adolescent team members about disease related concerns as well as life events and stressors.</p> <p><b>Theme 2: Adolescent care as a time of disease-related learning and growth.</b> Individuals emphasised that they learned about their disease and how to both care for it and themselves and cope with their diagnosis.</p> <p>Transition  <b>Theme 3: A time of multiple challenges to navigate.</b> Most participants described feeling unprepared for transition and described anxiety and specific worries during the transition process. Participants indicated that the change was overwhelming. Worried included concerns about privacy and health status during transition.</p> <p><b>Theme 4: Recommendations for improving the transition process.</b> Participants recommended early communication and preparation for transition, options and control in the process and assistance with coordination and linking of services.</p> <p>Adult care  <b>Theme 5: A significant change in the experience of care.</b> Descriptions of adult care centred on differences in both the health care setting and the health care system. Young adults described increased concerns related to dealing more independently with insurance requirements, longer waits and/ or less time with providers.</p> <p><b>Theme 6: Opportunities for personal growth.</b> Participants also experienced adult care as marking a change in provider expectations and interactions. Many felt they were expected to be more responsible with making their appointments, arriving on time and making medical decisions, as compared to adolescent care. Adult care providers spoke more bluntly about their disease, lifestyle and treatment. They were described as less paternal and less flexible. Many of those interviewed felt that as adults they were making healthier choices and/ or had a more positive attitude about their health than when they were younger.</p>
Recommendations for successful transition	<p>Several participants recommended early communication about and preparation for transition, including a time period when both adolescent and adult care providers were being seen.</p> <p>Participants recommended that youth receive more options and control around choosing a new provider. They emphasised patients</p>

	<p>should be able to try different settings before settling on one. Priorities for adult care differed: some participants cared most about clinic location, while others were more concerned about privacy issues and others wanted to attend a clinic providing childcare or care to both mothers and children with HIV. Participants also indicated that options for care providers were important.</p> <p>All participants recommended that patients receive assistance coordinating the transition process, including help enrolling in mental health support and case management and assistance with the transfer of information between providers.</p>
Any negative impacts reported? <i>Yes/ No Individual/ organisational etc.</i>	No.
Limitations/weaknesses of study <i>As reported by authors</i>	Use of a small predominantly female convenience sample, and retrospective. Young adults in this study had successfully transitioned to adult care from a speciality paediatric clinic in an urban setting. Therefore these findings may not be applicable to those who do not transition to adult care.

<b>Vijayan et al 2009. We never thought this would happen: transitioning care of adolescents with perinatally acquired HIV infection from paediatrics to internal medicine, AIDS Care, 21 (10), 1222-1229.</b>	
Country: USA	
Relevant to review questions: 2, 3	
Study design: Qualitative study	
Method of data collection <i>e.g. 15 Semi structured interviews &amp; 2 focus groups</i>	<p>Individual open-ended interviews with 18 adolescents/ young adults (ages 12-24 years), 15 parents (12 adoptive parents) and 9 paediatric providers (5 attendings , 1 fellow, 1 nurse practitioner, 1 social worker and 1 research nurse) at the Yale-New Haven Children's Hospital Paediatric AIDS Clinic between November 2005 and April 2006</p> <p>Interviews lasted 30-60 minutes, were conducted by a single investigator not affiliated with the clinic and were open-ended questions and probes.</p> <p>Used a written questionnaire (completed after interview) regarding history of sexual activity and drug use as well as a health literacy test, Rapid Estimate of Adult Literacy in Medicine (REALM) which calculates a grade equivalent.</p>
<b>INTERVENTION</b>	
Description of model/ intervention	No intervention for transition in place – study relates to young peoples' experiences of transition as it happened.
Theoretical model (if given)	None
Condition <i>e.g. diabetes</i>	HIV
Comparator?	n/a
Setting	Yale Pediatric AIDS Care Programme, New Haven, Connecticut
Who delivered it?	n/a
Description of model/ intervention	n/a
<b>POPULATION</b>	
Target recipients ( <i>who it was</i> )	Adolescents who came to the clinic during the study period and met

<i>aimed at) e.g. age, sex, health condition</i>	the following criteria were eligible: (used purposeful sampling) (1) Had vertically transmitted HIV (2) Did not have a clinical diagnosis of substantial cognitive limitation (3) Were 12-24 years old
Outcomes for individuals: <i>List outcomes, how each was measured (e.g. scale), who measured it and when it was measured.</i>	Outcomes from interview not specifically stated but covered: <ul style="list-style-type: none"> <li>• Challenges to caring for adolescent with HIV.</li> <li>• Barriers to transitioning adolescents to adult-oriented health care systems.</li> <li>• History of sexual activity and drug use – used confidential written questionnaire.</li> </ul>
Clinical/ health outcomes	None.
Service delivery, organisational outcomes. <i>List outcomes</i>	<i>n/a</i>
<i>Whose perspective? List whose views, if any, are reported (e.g. patients, parents, caregivers)</i>	Patients, their parents and paediatric providers at the Yale-new Haven children's Hospital Pediatric AIDS Care Clinic
Costs/economic matters <i>State whether paper contains any economic info.</i>	<i>n/a</i>
Key process issues - Barriers	<p><b>Barriers to transitioning adolescents to adult-orientated health care systems</b></p> <ul style="list-style-type: none"> <li>• <b>Families' negative perceptions of and experiences with HIV disease</b> Most adolescents had not disclosed their HIV status to their peers; some conveyed fear of stigma surrounding the disclosure of the disease and general lack of trust toward peer groups and other social networks.</li> <li>• <b>Perceived lack of autonomy</b> Providers felt that because these adolescents had never been expected to live for very long, they were never taught the life skills needed to survive independently. Regardless of their age, a number of adolescents were unable to state what medication they took and with what frequency.</li> <li>• <b>Difficulty letting go of the relationship between paediatric providers and families</b> Parents, adolescents and providers all conveyed a sense of difficulty terminating their relationships because of a sense of a familial relationship within the paediatric AIDS care program. Providers had a difficult time letting go of their relationships with families and feared that adult clinics would not provide as welcoming a setting as the paediatric clinic.  Most adolescents did not achieve their expected level of literacy.</li> </ul>
Key process issues – facilitating factors	None
Key issues for young people	<p><b>Challenges to caring for adolescents with HIV</b></p> <ul style="list-style-type: none"> <li>• <b>Difficulty with adherence to medication regimen</b></li> </ul>

	<p>Non-compliance often was due to fear of disclosure, as adolescents felt uncomfortable in taking medicine around their peer groups. Most adolescents either depended on their parents to help them take their medications or would not take them at all, especially when feeling well. The act of taking medication was said to be a negative reminder of the disease. Most study participants could not name their medications.</p> <ul style="list-style-type: none"> <li> <b>Difficulty with adolescent sexuality</b>            Adolescents were often unable to disclose their HIV status to their intimate partners, presenting a significant public health challenge to providers. Providers expressed concerns both about the lack of resources for sexual health care in the paediatric-orientated clinic (specifically gynaecologic care) as well as about the issue of partner notification.         </li> <li> <b>Disorganised social environments</b>            Providers explained that living in such environments significantly affected many adolescents' emotional and psychological well-being, their perception of their HIV disease, and their adherence to their medication regimen. Children were prevented from benefitting from supportive social networks in part because their social environment was disrupted and in part because of the stigma conveyed by their disease and the subsequent social isolation.         </li> </ul>
<p>Recommendations for successful transition</p>	<p>Adult-orientated providers should be aware of the specific challenges regarding adolescents with HIV. In particular stigma played a prominent role in both challenges to care and barriers to transition and is an aspect of the disease that may significantly impede access to health care.</p> <p>Having paediatric providers continue to be involved directly in the adult-orientated setting, by inviting adult providers to the paediatric setting, or by specifically creating transitional clinics for adolescents may provide an effective bridge to transition.</p> <p>Adult-orientated care providers need to be aware of the protected healthcare environment from which these children come and may have to tailor their language and approach to interacting with patients who have been followed in a paediatric HIV clinic.</p> <p>Providers should take care to address patients' limited autonomy by working with them to take control of their healthcare and find ways to help them to manage the stigma that they face daily.</p> <p>Paediatric HIV care providers may need to be aware of their own reluctance to let go; and they will need to address the issues of transition at earlier ages, ones that acknowledge the sexual precocity of many adolescents.</p> <p>Having ample dialogue between paediatric and adult HIV care teams, preparation of patients and their families via specific transition plans and robust support structures that address stigma, limited autonomy, and the many other challenges to growing up with HIV.</p>
<p>Any negative impacts reported?</p>	<p>n/a (no model)</p>

Yes/ No Individual/ organisational etc.	
Limitations/weaknesses of study As reported by authors	With respect to generalizability- they used a modest sample of adolescents and cannot be sure that the results would apply more broadly.
Any other comments	

<b>Wiener LS, Kohrt BA, Battles HB, Pao M. The HIV experience: youth identified barriers for transitioning from paediatric to adult care. Journal of Pediatric Psychology 2011 36 (2) 141-154</b>	
Country: USA	
Relevant to review questions: 2, 3	
Study design: Qualitative, with a quantitative analysis of CD4 counts	
Method of data collection e.g. 15 Semi structured interviews & 2 focus groups	59 semi-structured telephone interviews. 5-10 minute phone interview. Interviews were hand recorded. Data were collected from 80 youths yielding a response rate of 89% (data for minors were obtained from the primary caregiver).
<b>INTERVENTION</b>	
Name/ nature of model (if described)	Between 1986 and 2005, 550 children/adolescents were evaluated for treatment in a paediatric HIV programme at a large medical research facility. Youths who enrol on a clinical trial at this facility travel to and from their home community in order to participate in the research and obtain their HIV treatment and care. Travel is provided for the youth and one primary caregiver. In December 2004 an administrative decision was made to close the programme. The programme officially closed in October 2005. The aim of the study was to explore the transition experience of HIV positive youth who were enrolled in a clinical trial or psychosocial protocol at the time of the program closure. Participants transitioned to adult or paediatric care in their home community. They were interested in exploring whether individuals who transitioned to adult health care providers would have equal or better health status post-transition and to better understand youth-identified key issues for a successful transition of care to occur.
Theoretical model (if given)	Not reported
Condition e.g. diabetes	HIV
Comparator?	None in this study. (Compared results from those who participated in study and those who were unable to be contacted: No significant differences were found in CD4 ( $t(86)=1.1, p=.29$ ), gender ( $X^2(1) = .09, p=.77$ ), mode of transmission ( $X^2(2) = .68, p=.71$ ), or trace ( $X^2(3)=.81, p=.85$ )
Setting	Single setting. Participants had been enrolled on clinical trials at 'a large medical research facility' when administrative decisions were made to close the programs. They were then transitioned in their 'home community'
Who delivered it?	Not reported
Description of model/ intervention	Not reported
<b>POPULATION</b>	
Target recipients (who it was aimed at) e.g. age, sex, health condition	Young adults or adolescents living with HIV aged 18+ were recruited for the study and asked about their experience of transition to adult HIV care. 51% male, mean age 22y (range 18-30), 44% Caucasian, 41% African American, 9% Hispanic, 7% other. 51% living with parents.



<p>Individual outcomes <i>List outcomes, how each was measured (e.g. scale), who measured it and when it was measured. Use another form for actual results?</i></p>	<p>Questions pertained to:</p> <ol style="list-style-type: none"> <li>1. Current health status and medication regimens,</li> <li>2. Whether participant had medical insurance</li> <li>3. If transition to adult care had occurred, whether the transition was as expected, better than expected or more difficult than expected.</li> </ol> <p>Participants were also asked whether they had faced any challenges or difficulty obtaining services or adhering to a medication regimen or schedule since the transition occurred. Physical health status was measured by participants' CD4 count obtained during their last clinic visit prior to program closure and self report of their most recent CD4 count.</p>
<p>Clinical outcomes</p>	<p>No significant difference in CD4 counts before and after transition.</p>
<p>Service delivery, organisational outcomes. <i>List outcomes</i></p>	<p>Challenges or difficulty obtaining services.</p>
<p><i>Whose perspective? List whose views, if any, are reported (e.g. patients, parents, caregivers)</i></p>	<p>Patients.</p>
<p>Costs/economic matters <i>State whether paper contains any economic info.</i></p>	<p>None.</p>
<p>Key process issues - Barriers</p>	<p>See 'recommendations'. A barrier specific to this population was the perceived increase in stigma on transitioning to adult care.</p> <p>In this study three of the four most frequently endorsed barriers were relational in nature: the need for more personal and consistent care, improved communication, and consideration of developmental level. Willingness of paediatric provider to let go as well.</p> <p>The number of youth whose biological parents are deceased is unique to this population. Anxiety may be associated with having to break ties from providers with whom these youth have had close relationships and may have known their parents before their death which may compromise a successful transition.</p> <p>A new medical environment brings the expectation of new relationships and the challenge of learning to trust all over again. Young adults may be reluctant to confide in a new provider, feeling that the provider may disclose information to their primary caregivers or condemn their behaviours.</p>
<p>Key process issues – facilitating factors</p>	<p>See 'recommendations'</p> <p>Facilitating factors suggested for a successful transition</p> <p>Almost a third of this sample has been hospitalised over the past 3 years demonstrating that close medical and psychiatric monitoring is vital. Almost a quarter of the participants over 18 are not working or in school. This finding suggests that preparation for transition should include an assessment of vocational needs, educational plans, encouragement of work experiences and a vision for future employment along with life skills training.</p> <p>There was a perceived change in stigma upon transitioning to adult</p>

	<p>care. The adult care setting typically has a more diverse client base and newly transitioning young adults would benefit from being prepared for coming into contact with people whose age, sexual orientation, mode of transmission and severity of illness may be different from their own.</p> <p>A coordinated approach where communication between paediatric and adult providers takes place prior to and if clinically indicated, after the transition takes place, can reduce the sense of loss and feeling of abandonment. Having an individual maintain contact for several months after leaving the paediatric programme, if feasible may reduce the anxiety and sense of loss.</p>
Key issues for young people	<p><i>45% found the transition more difficult than anticipated, and 32% could not find emotional support services.</i></p> <p><i>Youth identified the need for</i></p> <ol style="list-style-type: none"> <li><i>(1) Increased continuity and quality of care</i></li> <li><i>(2) Assistance with the logistical aspects of transition</i></li> <li><i>(3) Improved communication between all parties involved in transition</i></li> <li><i>(4) Acknowledgement of the developmental level of the patient and use this to individualise the amount of autonomy granted to the patient</i></li> <li><i>(5) Have adult providers learn skills specific to the treatment of youth with HIV</i></li> <li><i>(6) Interdisciplinary services, specifically mental health and case management</i></li> <li><i>(7) Preparation of youth for changes in atmosphere at adult settings</i></li> <li><i>(8) Paediatric providers need to encourage transition rather than impeding it</i></li> </ol> <p>Many children born with HIV in the epidemic were not expected to survive to adulthood. Becoming academically or emotionally prepared for independent living or decision-making was not a priority for most primary caregivers or providers. With the advent of highly active anti-retroviral therapy HAART, survival is now expected. The need to help these youths catch up academically and emotionally by reducing dependence on their families has become necessary for day to day living as well as transitioning care. This was expressed by participants who reported difficulty with relaying their own medical history, their expressed desire to keep their primary caregivers involved in their care and reluctance by either primary caregivers or paediatricians to give up control of their healthcare.</p> <p>29% of those hospitalised were admitted for psychiatric reasons, and a third of participants that transitioned identified a lack of support services. With almost 10% of the total cohort reporting having had a psychiatric hospitalisation over the past 3 years, the availability of mental healthcare appears to be critical component to a successful transition.</p> <p>Almost a quarter of youth interviewed said adult providers seemed to have limited understanding of the psychosocial issues of this age group. They need to address common concerns of young people including sexuality, substance use and other health promoting and harming behaviours.</p>

	Unplanned pregnancies and unsafe sex was practiced: there is need to incorporate secondary prevention messages primary care for this population
Recommendations for successful transition	<ol style="list-style-type: none"> <li>1. Increase continuity and quality of care. Important to have rapport with doctor or healthcare team. Patients wanted continuation of individualised care that they received as paediatric patients. Seeing same doctor each time would help.</li> <li>2. Provide assistance with the logistical aspects of transition. E.g. help in locating an adult provider. Paediatric providers releasing medical records, help with paperwork, help with getting to appointments, help with insurance issues.</li> <li>3. Improve communication between all parties involved in transition: between paediatric and adult providers; between patients and paediatric providers and between adult providers and primary caregivers / parents.</li> <li>4. Acknowledge the developmental level of the patient and use this to individualise the amount of autonomy granted to the patient. Providers assumed that patients were ready to take responsibility for their own care but some would prefer not to be treated as adults immediately. Some mentioned a program for young adults.</li> <li>5. Have adult providers learn skills specific to the treatment of youth with HIV. Participants felt the inclusion of primary caregivers in decision-making and treatment planning was critical, especially directly following transition from paediatric care and particularly with youth with special developmental needs.</li> <li>6. Provide interdisciplinary services, specifically mental health and case management. Adult providers do not address all patients' needs, specifically concerns about sexual activity, pregnancy and disclosure.</li> <li>7. Prepare youth for changes in atmosphere at adult settings. Different population and atmosphere can increase anxiety.</li> <li>8. Paediatric providers need to encourage transition rather than impeding it. To ease transition some participants wished they had been given more responsibility while still in paediatric care where they could make mistakes but also learn to build the necessary competencies for self-management of care.</li> </ol>
Any negative impacts reported? <i>Yes/ No Individual/ organisational etc.</i>	Adult setting can increase anxiety and stigma.
Limitations/weaknesses of study <i>As reported by authors</i>	This study has several limitations including the brief telephone survey design. While telephone interviewing has a number of advantages over face-to-face interviewing, such as providing a focused, time sparing and convenient way to obtain data from a geographically dispersed sample, the data only includes patient self-report, which is subject to recall bias. In particular, the self-reported CD4 counts are not as reliable as the pre-transition chart values. Second they assessed adherence via self-report, as employing objective measures to validate adherence was not feasible. Therefore the results should be viewed with some caution.

	<p>Third, participant confirmation of qualitative results was not obtained, that is, answers were not sent back to the participants to ensure accurate understanding and interpretation of the comment provided. This presents some concern regarding examiner bias. While the division of interviewing, transcribing and coding responsibilities prevented overlap between the researcher asking the question and the researcher interpreting it, future studies should not neglect this step of returning the results to the participants to ensure accuracy.</p> <p>Fourth, as this was a brief descriptive study of the transition process, we were not able to employ measures to assess mental health status or family environment and therefore could not address other potential predictors or indicators that can potentially influence the experience of transition. They were also restricted to only conducting interviews with participants ages 18 and older.</p> <p>Fifth is the single-institution setting, while the good response rate reduces the concern for selection bias, a more demographically representative sample of peri-natally HIV infected adolescents can help determine the extent to which the findings are generalisable to all youth seen in paediatric HIV programs.</p> <p>Lastly the intention of this study was to learn about the experiences of those youth who have transitioned out of paediatric care. The data do not answer the question of how long the transition preparation should take or the best age to introduce or make the change, but rather highlights what the participants found most challenging and the importance for future work to be conducted on this topic.</p>
Any other comments	Have classified this as a qualitative study as the quantitative element (CD4 count) is only reported briefly.

<b>Wong L, Chan F, Wong F, Wong E, Huen K, Yeoh E, Fok T (2010) Transition care for adolescents and families with chronic illnesses. Journal of Adolescent Health 47: 540-546.</b>	
Country: Hong Kong.	
Relevant to review questions: 2 & 3.	
Study design: Quantitative. Cross-sectional study.	
Method of data collection <i>e.g. 15 Semi structured interviews &amp; 2 focus groups</i>	137 adolescents aged 16-19 years and 67 parents completed a self-administered, anonymous questionnaire.  Patients completed the questionnaire at their out-patient clinic when they came back for their regular clinic follow-up.
<b>INTERVENTION</b>	
Description of model/ intervention	<i>Not given.</i>
Theoretical model (if given)	Not stated.
Condition <i>e.g. diabetes</i>	Common chronic conditions. Asthma, diabetes, epilepsy and thyroid diseases were identified as the common pediatric chronic diseases.
Comparator?	
Setting	Pediatric out-patient clinic
Who delivered it?	
Description of model/ intervention	Self-administered questionnaire to explore attitudes of adolescents with a chronic condition and parents towards transition care and to identify factors and barriers associated with transition decision in Hong Kong.
<b>POPULATION</b>	
Target recipients ( <i>who it was aimed at</i> ) <i>e.g. age, sex, health</i>	Adolescents with a chronic disease requiring long-term follow-up at the pediatric clinic, and who were likely to have their diseases

<p><i>condition</i></p>	<p>extending into adulthood, together with their parents, were recruited from a regional hospital in HK.</p> <p>Adolescents were 16-19 years. A total of 55% of adolescents = females.</p> <p>Parents aged 32-58 years and 85% = females.</p> <p>Adolescents with asthma, diabetes, epilepsy and thyroid disease, including Grave's disease and hypothyroidism, were recruited (49.2% asthma; 7.7% diabetes; 13.8% epilepsy; 23.1% thyroid diseases). All the eligible patients identified from the CDARS (Clinical Data Analysis and Report System) of the Hospital Authority and individual clinic attendance lists were approached, the aim being to recruit all adolescent patients with the selected chronic diseases followed up in that regional hospital.</p>
<p>Outcomes for individuals: <i>List outcomes, how each was measured (e.g. scale), who measured it and when it was measured.</i></p>	<p>Participants' perceptions of transition care. Perceived severity and chronicity of adolescents' health problem, Perceived physician's effectiveness, Attitude toward transition care, Factors and barriers affecting transition decision, Demographics including age, gender, education level, family structure, socioeconomic status, parental education. Participants' also invited to give suggestions re. how to implement smooth transition.</p>
<p>Clinical/ health outcomes</p>	<p>Not reported.</p>
<p>Service delivery, organisational outcomes. <i>List outcomes</i></p>	<p>Not reported.</p>
<p><i>Whose perspective? List whose views, if any, are reported (e.g. patients, parents, caregivers)</i></p>	<p>Adolescents and parents.</p>
<p>Costs/economic matters <i>State whether paper contains any economic info.</i></p>	<p>No.</p>
<p>Key process issues - Barriers</p>	<p><b>"Do not want to change" was the only significant barrier for transition for both adolescents and parents.</b></p> <p>Other potential barriers such as not understanding transition care, fear of new environment or maladjustment, not the right time for transition, not ready to accept transitional care, all had no significant effect on adolescent's willingness to change.</p> <p>Main hurdle was inadequate support from providers and lack of appropriate setting.</p>
<p>Key process issues – facilitating factors</p>	<p><b>"Adolescent's perception of his/her own responsibility towards chronic illness" was positively associated with willingness to transfer to adult care.</b></p> <p>Other independent variables such as acceptance of disease, trust to current doctor and confidence to future doctor were found to be non-significant. Also, no significant difference in transition decision in different genders, age groups, chronic disease type or severity of disease.</p>

	<p><b>“Detailed explanation by doctors” encouraged transition decision for adolescents.</b></p> <p>Appropriate transition info, adequate time to prepare transition, psychological preparation before transition and temporarily providing transition care at combined pediatric-adult clinic showed no significant effect. No significant factor was found facilitating parents to make transition decision.</p>
Key issues for young people	
Recommendations for successful transition	See facilitating factors above.
Any negative impacts reported? <i>Yes/ No</i> <i>Individual/ organisational etc.</i>	Lack of providers’ awareness on transition care. Less than 10% of participants had ever received any transition information from HCPs.
Limitations/weaknesses of study <i>As reported by authors</i>	<p>Cross-sectional study which could not provide any causal relationship between outcomes and factors. Data collected from one regional hospital and results might not be generalizable to all adolescent population in HK.</p> <p>Current results did not include views of adolescents already transitioned to adult care.</p> <p>Data from parents was limited because many older adolescents came back for follow-up without being accompanied by their parents.</p> <p>Study did not include perspectives of paediatricians or adult physicians.</p> <p>In this study all eligible adolescents and parents in the hospital were approached. However, 36 patients defaulted follow-up despite repeated reminders. This group could be at higher risk of having poorer transition outcomes.</p>
Any other comments	This study did not address barriers on providers’ side. Would be beneficial to understand practical difficulties of physicians in implementing transition model.

<b>Young N, Barden W, Mills W, Burke T, Law M, Boydell K (2009) Transition to adult-oriented health care: perspectives of youth and adults with complex physical disabilities. <i>Physical and Occupational Therapy in Pediatrics</i>, 29(4): 345-361.</b>	
Country: Canada	
Relevant to review questions: 2, 3	
Study design: Qualitative	
Method of data collection <i>e.g. 15 Semi structured interviews &amp; 2 focus groups</i>	<p>Semi-structured individual interviews with 15 youth (14-18 years) and 15 adults (24-32 years) with cerebral palsy, spina bifida and acquired brain injuries of childhood who received clinical care from one of the six Children’s Treatment Centres in Ontario. Participants were purposively sampled from larger study, in which survey data had been collected from 190 youths and 100 adults.</p> <p>A separate interview was conducted concurrently with participants’ parent/primary caregiver (n=30).</p> <p>Sample limited to Ontario residents and included representation from several distinct geographical regions.</p>
<b>INTERVENTION</b>	
Description of model/ intervention	
Theoretical model (if given)	Not stated.
Condition <i>e.g. diabetes</i>	Complex physical disabilities – CF, SB and ABIC.

Comparator?	No.
Setting	Children's Treatment Centres, Ontario.
Who delivered it?	One research associate and one research assistant.
Description of model/ intervention	Exploration of transition to adult-oriented health care in a Canadian context.
<b>POPULATION</b>	
Target recipients ( <i>who it was aimed at</i> ) e.g. age, sex, health condition	15 youth (14-18 years) and 15 adults (24-32 years) with cerebral palsy, spina bifida and acquired brain injuries of childhood. Plus, 30 participants' parent/primary caregiver.  Sample covered full spectrum of physical disability (27% mild, 43% moderate, 30% severe).  20% from rural regions. 10% from small cities. 43% from metropolitan cities.
Outcomes for individuals: <i>List outcomes, how each was measured (e.g. scale), who measured it and when it was measured.</i>	Anticipation or experience of health care transition. Factors affecting outcome of transition.
Clinical/ health outcomes	Not stated.
Service delivery, organisational outcomes. <i>List outcomes</i>	Health care services received in childhood and in adult-oriented care.
<i>Whose perspective?</i> <i>List whose views, if any, are reported (e.g. patients, parents, caregivers)</i>	5 youths who had not yet started transition. 3 youths who were in process of transition. 7 youths and 15 adults who had completed transition.  Themes below explored to determine if any were unique to diagnosis, stage of transition, gender, severity or region of residence. Barriers and solutions were common across sample, but not unanimous. Variations related to diagnosis, region of residence and stage of transition, but no unique patterns found related specifically to gender.
Costs/economic matters <i>State whether paper contains any economic info.</i>	No.
Key process issues - Barriers	1. Lack of access to health care professionals (= most important issue) and especially, lack of access to physician specialist and allied health professionals due to age limit, i.e. after age 18 age criteria imposed by pediatric health services, which means youth not eligible (78% of respondents discussed this). 2. Lack of professionals' knowledge (56%). 3. Lack of information (55%). Particularly pertinent for parents of youth with disabilities. 4. Uncertainty regarding transition process (60%).
Key process issues – facilitating factors	See recommendations below.
Key issues for young people	See recommendations and negative impacts below.
Recommendations for successful transition	1. Early provision of detailed information and more information throughout transition process directed at youths and not solely

	<p>parents (52%).</p> <p>2. More extensive support (from HCPs, family, friends, etc.) throughout the clinical transition process- before, during and after (50%).</p> <p>More emphasis needs to be placed on educating medical trainees regarding assessing and treating people with disabilities.</p>
<p>Any negative impacts reported?  <i>Yes/ No</i>  <i>Individual/ organisational etc.</i></p>	<p>Concerns focused on loss of long-term relationship and of someone with historical knowledge of condition and clinical expertise.</p> <p>Access to care following transition was found to be challenging.</p> <p>Concerns expressed re. types of services eventually accessed.</p> <p>Concerns re. health care experiences in hospitals and emergency rooms.</p> <p>Even following transition a large percentage continued to have uncertainty re. transition process.</p>
<p>Limitations/weaknesses of study  <i>As reported by authors</i></p>	<p>Not stated.</p>
<p>Any other comments</p>	