

# Transition of care from children's to adult services

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# **Title page**

## **Title:**

Achieving Excellence in care by Supporting Transition from Children's to Adult services: A review of the literature

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**Keywords:**

Health care transition, adolescence, Health services research, Chronic illness, intervention evaluation, literature review.

**Abstract**

Transition service development is currently high on the agenda within contemporary healthcare improvement; there is a wealth of literature focusing upon shortcomings of many existing transition services. This narrative review aims to collate and review some of the key literature regarding the current evidence, patient; parent and staff experience and the identification of existing interventions which have been implemented and evaluated within these services. Key points have been extrapolated with the key findings and key learning points identified which can be taken utilised within future service developments.

**Word count:**

2940

## **Introduction**

The transition from childhood to adulthood is recognized as a time of physical, emotional, social and psychological change for young people. However, for those with complex health needs this is compounded by additional challenges surrounding how their healthcare is provided. It is recognised that these young people need to understand, adapt and engage with services which are often drastically different to the care services they have historically received (Care Quality Commission, 2014; Campbell et al., 2015 and NICE, 2016;).

Transition from children's to adult services continues to be the focus of much contemporary health and social care research, as well as the focus of evaluation by healthcare regulatory bodies such as the Care Quality Commission (CQC). There is a growing understanding of the potential implications for healthcare service that do not meet the specific needs of young people at this important stage of life as these individuals are likely to fall into a poorly managed 'care gap' which is associated with significantly worsened health outcomes.

There has been a distinct move away from the focus of transition as a one off event to that of a gradual process over time. This contemporary standpoint indicates that there are multiple opportunities for professionals to engage with young people to support them. However, consensus of the appropriate ways to support young people during this time remains unclear.

### **Aims of the review:**

The aims of this review are to:

Identify and summarise the literature that reports the issues/needs surrounding transitional care from children's to adult services.

Explore critique and evaluate the effectiveness of interventions, processes and systems relating supporting transitions for young people between children and adult services that could be further explored and/or implemented in practice.

Please note that throughout this paper the terms ‘young person’, ‘young people’ and ‘adolescent’ are used interchangeably.

## **Methods**

From the period of June- August 2016, a literature review was conducted to identify both empirical and review papers pertinent to understanding current transition services from paediatric to adult health care services and how these services are developed and evaluated.

Searches were conducted primarily through the use of electric database search engines to identify relevant studies (CINAHL, Medline and EMBASE). Key terms used included:

- ‘Adolescents’
- ‘Young adults’
- ‘Chronic illness’
- ‘Intervention’
- ‘Healthcare transition’.

Searches were limited to studies reported in English language and papers were limited to those published from 2005-2016 to ensure they reflected context of contemporary health services and clinical care. Following the identification of relevant papers from the searches, their reference lists were reviewed to identify further sources of relevance.

## **Results and Discussion**

### **Young people's experiences**

There is a wide breadth and depth of research focusing on young people's experiences and perspectives of transition and transition services. Betz et al., (2013) conducted a systematic literature identifying 35 empirical research studies including exploring young people's perspectives of transitional care. Similarly Fegran et al (2013) conducted a qualitative meta-synthesis of 18 research studies including perspectives of 368 young people.

Findings from these reviews identified that young people were not sufficiently informed or prepared for the changes they would experience during transition. Furthermore, many illustrated a lack of understanding of future expectations from adult services and the expected outcome of the transition process (Betz et al 2013). It is evident that there is a clear consensus especially from qualitative research that highlights young people feel that services have failed to provide for their needs during transition (Fegran et al., 2013; Betz et al., 2013; CQC, 2015). Many young people discuss negative experiences of transition including: feelings of being lost and abandoned; anxiety around difficulties in changing relationships; moving from familiar to the unknown; feelings of unpreparedness and challenges surrounding achieving responsibility during transition to adult services (Fegran et al., 2013). However, there are other studies in which young people do speak positively of their experiences of transition or parts of their transition journey (Belair et al., 2011), but these remain scant.

Interestingly all included studies adopted descriptive designs, with data collection comprising of interviews or surveys. Betz et al., (2013, p.21) identify that many of the designs and methods used to explore and understand transition 'reflect a field of study that is in the early

stages'. However, this evidence does provide a useful knowledgebase from which to develop and test future interventions.

## **Parent and carers experiences**

Parents and carers are often one of the only constants in a young person's life and therefore they can be pivotal in supporting young people to navigate transitioning to adult services, this distinctive and fundamental role within the transition process is clearly documented within guidelines and frameworks (CQC 2014, NICE 2016). Incongruously with this the role of parents within the healthcare systems and the expectations of healthcare providers are dramatically different in paediatric and adult health care services, there are reports of this leaving parents overburdened, feeling forced out of their child's care and stranded in a system which they don't fully understand (Sonneveld, 2012; CQC, 2014; Nyuyen, 2016)

Again there is a growing body of evidence exploring parent experiences of transition Nguyen et al., (2016) undertook a qualitative study utilising semi structure interviews to explore self-management from the perspectives of young people (n=11), parents ( n=7) and healthcare professionals (n=7) involved within the transition process. Interestingly most of the parents and professionals in this study talked about the importance of relying on each other to assist a young person in self-management. Parents also identified the importance of professionals adapting a gradual and developmentally appropriate approach when transitioning young people and parents to adult services.

Sonneveld et al., (2011) undertook an explorative study to compare young people (n=138), parents (n=181) and healthcare provider's (n=19) perspectives of transitional care utilising the 'mind the gap' questionnaire. Young people consistently scored lower in satisfaction around provider characteristics than parents. However, parents were significantly less happy in management of the healthcare environment. Findings also identified that both parents and

young people showed high levels of dissatisfaction with the transitional care process. Whilst the perspectives and priorities of parents may be different to those of young people, this is an area of research which supports claims within key documents that transition services are often failing to meet the needs of parents as well as young people.

### **Healthcare provider roles, knowledge and competency in providing transition services**

It is recognised in the literature that many challenges surrounding transition are attributable to healthcare services and professionals being focused on either the needs of children or adults and not young people (Gleeson and Turner, 2012; CQC 2014; Nehring et al., 2015,). The Kennedy report went as far as to describe adolescent transition as a ‘phenomenon created by the system’ (DH, 2010). This was also reflected in the recent CQC report where healthcare professionals did not feel equipped to manage the transition process as they lacked knowledge about the specific needs of young people (CQC, 2014). These comments have been confirmed by healthcare professionals, who when asked, identified a number of barriers to transition services including inadequate training; lack of understanding of needs of young people; and problems with access to transition resources (Nehring et al., 2015).

It has been proposed that the provision of training in adolescent health has been associated with sustainable, large improvements in knowledge, skills, and self-perceived competency of healthcare professionals (Sansi, 2000; Sansi, 2005,). Studies have been conducted in an attempt to explore and address unmet educational needs which include the testing of different educational interventions. These include: structured training programmes for nurses (Lee and Wang, 2016); online training resources for medical staff (Saudi, 2011); and multifaceted education programme for GP’s (Sansi, 2000). With the exception of Sansi et al., (2000), who conducted an RCT with five year follow up, all of the studies available consist of small



convenience samples and have adapted a descriptive study design. Therefore there is limited empirical evidence to substantiate the efficacy of these interventions. It is evident that this is an area requiring further research as there remains to be no templates of best practice and specific training standards (Nehring, 2015).

## **Development and evaluation of interventions**

There is a growing body of literature focusing upon developing and evaluating specific healthcare interventions aiming to improve transitional care. Intervention types and outcomes employed to assess efficacy vary with interventions ranging from those focused on the individual (young person, parent or health care professional), to those affecting organisational structures and health care processes.

Campbell et al., (2015) undertook a literature review of all available RCT's, before and after studies, and interrupted time-series studies. The four identified studies collectively included 238 participants and evaluated interventions focused upon on the patient and included:

- A two day workshop based transition training (spina bifida),
- A nurse led 1:1 teaching session with additional support of health passport (heart disease),
- A web based and SMS educational intervention for adolescents (range of conditions),
- A structured transition programme with a transition coordinator (diabetes).

Results identified that the efficacy of the different interventions were varied. However from the assessment of transitional readiness it was evident from the findings that the 1:1 nursing intervention and web based interventions may have improved readiness. In measures of self-care and general health behaviours, knowledge of disease may have also improved with the 1:1 intervention. However, the review authors concluded that due lack of robust study design

the certainty of the body of evidence is low, and thus it was difficult to draw any firm conclusions about the effectiveness of the interventions.

Similarly, Crowley et al., (2011) identified the benefits of patient specific interventions following their systematic review examining 10 studies these adopted a variety of different study designs and all evaluated outcomes which were either health outcomes (including HbA1c and creatinine levels) or health service use (including number of missed appointments). Of the 10 interventions programmes, six studies that included either disease specific education or generic education/skills training showed significant improvements. However, findings are limited as many of these studies included multiple interventions which were delivered simultaneously.

Chu et al., (2015) undertook a systematic review of discrete transition interventions. Five empirical studies evaluating the efficacy of interventions based on the proportion of young people who successfully transferred to adult services were included. Three of the five studies showed that patients within the transition programmes had higher rates of successful transfer/higher rates of attendance within adult clinics than those who did not participant. This included the largest study (n=1507) indicating the benefits of joint adult and paediatric clinics (Nakhla et al., 2008). However, the other two studies found no statistically significance difference between the intervention and control groups.

Other staff based interventions, such as having named transition co-ordinators, have shown to improve patient outcomes in a number of research studies and service evaluations (Cadario et al, 2009; Crowley et al., 2011; CQC, 2014; Lewis and Slobovor, 2015). The role of the health care transition co-ordinator has also been widely examined and has been highlighted as essential within transitional services as discussed within the NICE guidelines further supporting the results of these studies.

## **Limitations with existing evidence of interventions**

It's clear within the literature that there remains to be many difficulties in comparing the effects and benefits of specific transition interventions. There is a consensus that whilst there is a wealth of literature exploring transition interventions the evidence base to inform practice is still weak due to the significant lack of research studies utilising robust research designs and rigorously evaluated interventions (Crowley, 2011; Chu et al, 2015; Campbell et al., 2015).

Many of the studies evaluated had small to medium size participant numbers and consisted of purposive or convenience samples. Furthermore very few studies involved a control group or adapted a RCT design and much of the research continues to adapt descriptive methodology with an over reliance on questionnaires and surveys. It has been suggested that this failing within the literature many have arisen because many transition intervention programmes are developed as clinical programmes and not research programmes (Chu et al., 2015). However, Campbell et al., (2016) did also comment that evidence from their review may be limited as many of the interventions that are more readily evaluated and therefore able to utilise more robust methodology may be less complex and thus more complex interventions which are potentially more difficult to evaluate might provide more significant outcomes.

In addition to the research methods, limitations also relate to the evaluation and comparison of transition interventions. This is attributed to the variety of types, intensity and duration of interventions which have been explored within the literature. For example Chu et al., (2015) reported that interventions varied from a one off event to those spanning over a 3 year period. It is therefore difficult to make direct comparisons between these different interventions to direct evidence based practice. Similarly many of these interventions were conducted with

specific patient groups or within specific healthcare systems which again reduces the generalisability of the results.

## **Conclusions and Recommendations**

Whilst this review not an exhaustive systematic review of all available evidence it is apparent from the evidence utilised that there is wide breadth of research available focusing on transition from children's to adults services. It is clear that some areas of transitional care have been heavily researched including the experiences of young people. Moreover, there has also been a large amount of research looking at specific interventions aimed at both young people and healthcare systems. It is evident from current evidence that a single faceted approach or intervention to support transition does not appear to be beneficial to all young people or be appropriate to all services. Therefore, it can be strongly suggested that there are no 'quick fix' interventions that can be implemented to all services to facilitate and support transition (NICE, 2016). Whilst these studies offer valuable insight into young people's perceptions and experiences they are limited by sampling approach or use of instruments that are not validated. Furthermore, the impact of specific interventions are largely inconclusive.

### **Recommendations for practice and future research**

From the findings of this review there are a number of recommendations for practice and future research:

There is a large amount of research focusing on patient experience and perception of transition to adult services. This literature has been pivotal in the moving forward of transition services thus far and has provided the integral backbone of many key documents such as the Kennedy Report (2006) and CQC Report (2014) regarding transition. Going forward it is vital that young people continue to be central to all service change and

development regarding transition and young people's opinions should be actively sought throughout any such process. However it clearly can be argued that the benefit of repeating such research may be limited.

Professionals have been clearly identified as enablers and collaborators with parents (Nguyen, 2016), and the lack of understanding of the process of transition by healthcare professionals goes some way to explaining the lack of preparation reported by families (CQC, 2014). However it is also clear that this is an area of transition research which is in the early stages of development, further research of rigorous design and methodology is needed to fully understand the training needs of the interdisciplinary providers and translatable application in the development of training curriculums. Additionally research is needed to test the effectiveness of provider training models through the assessment of professional competency in delivering age appropriate, patient centred transitional services.

It is evident from both empirical research studies and contemporary guidelines that many healthcare providers both within adults and paediatric services continue to feel ill equipped to meet the specific developmental needs of adolescents. Research suggests professionals feel that training and development in this area would improve their confidence in providing these services. There has been a limited amount of research looking at the link between training for professionals and improved patient outcomes. As previously discussed it is clear that this is an area of transition research which is in the early stages of development. Further research using rigorous methodology is clearly needed in this area not only to establish the link between educational interventions for staff and patient outcomes but to enable the development of comprehensive training programmes.

There is a wealth of literature focusing on transition programmes and a number of interventions have been explored. However, there is limited literature indicating the optimum

method or tool to employ that will support transitional care in patients with chronic illness.

The evidence available regarding the impact of specific interventions on outcomes continues to be limited as many of the existing studies have combined a number of different interventions at the same time thus creating difficulty in ascertaining which intervention lead to improved outcomes when evident. There is a clear need for future studies to vary the components received to evaluate which specific interventions are most effective.

In order to meet the diverse needs of young people it is imperative that they are central and fully empowered to engage within all future transition service developments and evaluations (CQC, 2010; NICE, 2016; Campbell et al, 2016). However, it is clear from the literature that there is a distinct lack of empirical research studies focusing on the outcomes of specific interventions which have utilised robust research methodology (including randomisation and control groups for interventions) and person centred outcome measures. There is a need for future research to address deficits within this field of research. There is also a clear opportunity for further research which focuses specifically on the impact of interventions which target the organisation/delivery of care (such as joint clinics). These interventions have been evaluated in part, however the inferences that can be drawn remain limited due to lack of robust design/methodology.

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