

# **THE TRANSITION OF ADOLESCENTS WITH CHRONIC HEALTH CONDITIONS FROM PAEDIATRIC TO ADULT SERVICES**

## **LITERATURE OVERVIEW**

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**On behalf of**

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**Achieving Better Health Outcomes for Youth with Chronic Health Conditions: A  
Pan Disciplinary Approach**

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## Introduction

The following is a brief overview (rather than critical analysis) of the literature on the transition of young people with chronic health conditions from paediatric to adult health care services in high income countries. Health service transition is only one aspect of the transition from childhood to adulthood for adolescents with chronic health conditions and, although this review does consider how service transition connects to other aspects of life transition more broadly, it is primarily focused on the former rather than the latter. Because this review is concerned only with the health management of chronic conditions rather than the management of general health or other aspects of life, the term 'chronic health condition' here refers only to conditions that require ongoing monitoring and management to prevent or minimise mortality, morbidity and disability. This excludes conditions such as blindness/deafness and intellectual disability (except where they are associated with a medical condition). This avoids overlap with another study funded by an ARACY seed grant, convened by Dr Helen Leonard, entitled 'Leaving School: Maximizing participation and life outcomes in youth with an intellectual disability transitioning from secondary school to adult life', (see: <http://www.aracy.org.au/AM/Template.cfm?Section=HLeonard>). Issues particular to homeless, CALD or indigenous populations have not been addressed here either. However, our Collaboration is also preparing a review on this topic relevant to Australia's indigenous population.

Broad contextual factors of transition, such as the political, economic, national, local, structural, organisational and other social or health system contexts, are very important. However, it was not within the scope of this review to provide such analyses, given the complexity of these issues in countries like Australia, the UK and US where much of the research has taken place. For instance, health systems vary not only between but also within countries, ie from one state or borough to another.

Searches of electronic databases such as Medline and CINAHL were conducted, using keywords like: chronic conditions, adolescents, transition, service transition and health care. These searches were limited to the past 25 years in order to include some older seminal pieces, however the majority of this review focuses on articles published in the last 10-15 years. Existing bibliographies, such as the January 2007 version of the GMCT's References on Transition, were also used. Given the large number of relevant websites, such The Trust for the Study of Adolescence site or the Adolescent Health Transition Project website, it was not possible to include these in the search.

Despite the narrow parameters, around 300 core publications were uncovered, primarily journal articles but also including a small proportion of the 'grey literature' currently being produced at a fast rate by many levels of government and other organizations in the UK, US, Australia and elsewhere. Due to time limitations, the following review evaluates only a fraction of these core articles thus is by no means exhaustive. Rather it attempts to distil the major themes of the transition literature.

Given the size and nature of this body of work, there are numerous ways of viewing or analysing the literature. One would be to group studies by the type of chronic condition. Indeed, much of the literature is either specific to a particular condition and/or aimed at a particular group of health care professionals, (Cameron, 1985; Canobbio, 2001; Desir & Seidman, 2003; Myers, 2002). However, a lot of the

problems identified and recommendations made are generic to chronic illnesses generally (Sawyer et al., 1998). Another would be to analyse the research in terms of major arguments or debates, however, the literature is characterised by a great deal of consensus regarding most of the major issues. Given this, and the fact that the main purpose of this review is to summarise the current 'state of play' of the field, the following review is divided into five sections. The first clarifies the way in which service transition is generally defined in the literature and outlines the perceived benefits of a successful transition process. The second provides an overview of the numerous problematic aspects of transition identified in the literature. The third lists the equally numerous recommendations made to tackle these problems. The fourth summarises the findings of studies that have evaluated existing or pilot transition programmes to determine what does and does not work in practice. The fifth identifies the major gaps in the literature for future research.

## **1. Health Service Transition**

Whilst the term *transition* is often used to refer to the transition from childhood to adulthood, for the purposes of this review it refers to the move from paediatric services to adult health care. However, transition is much more than simply patient *transfer* - the singular static event or administrative transfer of a person from one health service to another. In 1993, the [American] Society for Adolescent Medicine defined transition as 'the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented health-care systems (Blum et al., 1993). In contrast, 'the current consensus statement reflects a more holistic set of goals highlighting the services needed to maximize lifelong functioning, not just preparation for new health care services' (Stewart, Antle, Healy, Law, & Young, 2007: 1). Certainly part of the literature continues to focus primarily on the clinical and administrative transfer of young people from paediatric to adult services, in particular the condition-specific medical implications (Desir & Seidman, 2003). However, much of the literature now also considers the psychosocial aspects of wellbeing as important as, or indistinguishable from, the physical wellbeing of young people with chronic health conditions. While this holistic approach is strongly reflected in this overview of the literature, the primary focus is on health system transition.

It is generally agreed in the literature that health services transition is an essential component of high-quality health care (Jackson & Pencharz, 2003). For instance, preliminary data from the first controlled trial of transitional care in any chronic illness showed significant improvement in health related quality of life, condition related knowledge, satisfaction in health care and vocational readiness markers (Robertson, McDonagh, Southwood, & Shaw, 2006: 74). Yet in Australia, as in numerous other countries, significant numbers of young adults with chronic conditions continue to receive their health care in paediatric units/hospitals beyond the point at which it would be appropriate for them to access adult hospital services (Sloman, 2005). For instance, a recent audit of an Australian children's hospital showed young adults aged 18 or over comprised 2% of admissions, a significant increase over a 10-year period (Lam, Fitzgerald, & Sawyer, 2005: 382). The study found that both the complexity of the condition and failure of transition planning contributed to the increased admission of young adults to the children's hospital and that, while greater support of transition planning is needed, there are also concerns about the lack of

appropriate services within the adult sector for young adults with complex, multidisciplinary healthcare needs (Lam et al., 2005). Adult clinics may simply lack the resources required to provide the multidisciplinary care common in paediatrics (Steinbeck, Brodie, & Towns, 2007).

In some cases, such as when a young person is in the terminal stages of illness, moving to adult care is inappropriate (Cowlard, 2003: 40). In most cases, however, the paediatric setting is inappropriate for young adults at many levels. Developmentally, for instance, 'there may be problems of developing sexuality and advice on contraception which are difficult to handle in the pediatric clinic or with heavy parental involvement' (Cameron, 1985: 94). Because paediatric centers are not equipped to cater for adults, they can encourage juvenile behaviour (Madge & Byron, 2002: 283). In cases where a chronic health condition has stunted the physical and psychosocial growth of a person, their continued treatment as 'children' in paediatric clinics may further delay rather than aid their process of maturation (Cameron, 1985: 94). At a medical management level, children receive optimal primary care in a medical practice experienced in the care of children and adults benefit from receiving care from physicians who are trained and experienced in adult medicine (American Academy of Pediatrics, 2002). Other benefits of transition are an increased sense of independence and control in the care decision-making process and general satisfaction in being treated as an adult (Miles, Edwards, & Clapson, 2004: 305). This is particularly important for adolescents with chronic health conditions who often have high levels of dependency on families and paediatric health care providers (Bent, Tennant, Swift, Scuffham, & Chamberlain, 2002; Fiorentino, Phillips, Walker, & Hall, 1998; Sawyer et al., 1998).

If, on the other hand, transition is stressful, difficult and traumatic, it can have a negative effect on the emotional and physical wellbeing of the young person (Brumfield & Lansbury, 2004). Poor transition results in measurable adverse consequences in terms of morbidity, mortality and long-term prognosis, as well as educational and social outcomes (Department of Health, 2006; Jackson & Pencharz, 2003). In the case of young people with disabilities, the support of health services (along with social care services) 'can be a major determinant of the extent to which people with disabilities can lead an independent adult life' (Fiorentino et al., 1998). In short, the health and wellbeing of young people with chronic health conditions can be compromised and their potential remain unrealised if transition is unsuccessful or inadequate (Forbes et al., 2001: 5).

## **2. Identifying the Barriers**

Despite these imperatives to get the transition process right, the general consensus in the literature is that transition procedures are *ad hoc*, inadequate, problematic or, in many cases, non-existent. This may be in part due to the fact that adolescence is effectively 'invisible' from the medical perspective, often perceived by many health professionals 'either as the end of childhood or the beginning of adulthood, rather than a discrete developmental phase in itself' (Sawyer & Bowes, 1999). It may also be partly due, in the case for instance of young adults with cystic fibrosis, to a paucity of adult clinics or a lack of expertise in adult medicine due to the great increase in adult survivors being only fairly recent (Madge & Byron, 2002). Similarly, some rare and

obscure conditions have until recently been virtually unknown in adult practice (Department of Health, 2006: 4).

The problematic aspects of transition identified in the literature are manifold and complex. Moreover, the scale of these problems has grown rapidly over the past generation or so as the survival rates of children with chronic illnesses to adulthood has improved dramatically due to recent advances in paediatric care (Laurvick, Christodoulou, & Ellaway, 2006; H. Leonard, 2005; S. Leonard, Bower, Petterson, & Leonards, 2000; Viola & Rosano, 2005). Happily, it is estimated that more than 85% of children born today with chronic medical conditions will live to adulthood (Reid et al., 2004: 611). However, many will have life-long or ongoing health care needs (While et al., 2004), thus adding a sense of urgency to the problems surrounding transition - undoubtedly a major factor in recent government interest in the issue, for instance in the UK and US.

The literature identifies a complex range of structural, financial, developmental and cultural barriers to successful transition (Sawyer et al., 1998: 414).

**Structural Barriers** - At a structural level major obstacles include: a lack of interagency planning (O'Sullivan, 2007: 3); differences in clinical practice and culture between paediatric and adult health care systems (Rosen, 1995; Sawyer et al., 1998); service configurations that frequently involve different care plans, care teams and funding arrangements (While et al., 2004: 439); and a 'lack of infrastructure and precedent in this specialised area of health care' (Bennett, Towns, & Steinbeck, 2005: 373). In some countries (e.g., the UK) there is also a failure of health services to communicate with other services that are important during transition, such as education departments and social services (Fiorentino et al., 1998).

**Individual Barriers** - Barriers are also formed at the level of the individual person, parent, carer and/or physician. For many young people with chronic health conditions, the thought of leaving trusted paediatric health professionals they have known all or most of their life can create a sense of loss, abandonment or uncertainty (Fiorentino et al., 1998). At the same time they may experience anxiety about leaving a familiar setting and having to meet and develop a relationship of trust with 'new' health professionals in an unknown setting (Bent et al., 2002; Cowlard, 2003; Sawyer et al., 1998: 415-6). In the case of young adults with cystic fibrosis, many fear moving to adult care because they equate adulthood with dying (Madge & Byron, 2002: 285). For adolescents with HIV, attending an adult clinic may mean encountering HIV-associated stigma (Miles et al., 2004). Indeed, if transition is not handled correctly and sensitively by health care professionals, young adults with chronic health conditions can become resistant, angry and/or defensive (Whitehouse & Paone, 1998). Some health professionals can also be 'reluctant to relinquish responsibility for the young people whom they have cared for through many stages of their lives, and whose complex needs they know in detail' (Bent et al., 2002: 1280). Understandably, parents too sometimes resist the move to adult health services, where young people are expected and encouraged to take more responsibility for their own health care and to see professionals on their own (Fiorentino et al., 1998: 267).

**System Gaps** - While some young people with chronic health conditions remain ensconced in paediatric services, others leave medical supervision altogether around

the time of transition, despite on-going health problems (Bennett et al., 2005; Reid et al., 2004; Sawyer et al., 1998). According to the literature, there are numerous reasons for this. In some cases it is simply due to a lack of information about options, services and support available (Beresford, 2004: 583). In others it is due to dissatisfaction with the reduced level of services within the adult system (Beresford, 2004; Fiorentino et al., 1998). Some young people, particularly those with neurological disability, have difficulty in finding an interested and competent service which is able and willing to provide continuity of medical care (Department of Health, 2006: 7). Irregular contact with services and gaps in the health system also allow young people to fall through health service nets and/or become lost in the system (Fiorentino et al., 1998). Another deterrent is that the adult system is often *ad hoc* and fragmented with a condition-specific focus which may compare unfavourably with paediatric services that are multi-disciplinary and nurturing. This can be exacerbated by the lack of interest many adolescents have in their own health care needs - they may be more concerned about leaving school and moving on to university, being with their peers or finding employment (Fiorentino et al., 1998). If they leave home, they may move out of the health service area altogether (Bent et al., 2002: 1280). Others may lack the confidence to contact the adult health professional to whom they have been referred (Fiorentino et al., 1998). For some it may be due to parents ceasing to take responsibility for their health care and check-ups (Bent et al., 2002: 1280).

**Ad hoc Services** - Even in cases where transition (or rather transfer) does occur, it frequently occurs by default rather than by design or abruptly with little or no preparation (Soanes & Timmons, 2004: 110). Within some health systems there is a great deal of confusion around the notion of 'transition' from one service to another' (Fiorentino et al., 1998: 260). Also, transition experiences can differ according to disability. For example, in one British study young people with spina bifida reported a smooth transition because of well-developed services for people with spinal injuries, whereas for young people with cerebral palsy there is no single services unit to cater for them, thus their referral path was unclear and their experiences of transition to adult services less positive (Fiorentino et al., 1998: 267).

**Uncoordinated Health Care** - At the other end of the medical transfer process a lot of adolescents find themselves 'hurtling into a void of uncoordinated or absent health services' (Chamberlain & Rooney, 1996: 88). This is particularly true for young people with conditions requiring multi-agency involvement because each participating organization often has different rules and practices regarding transition and there may be uncertainty about which agency has the responsibility for providing which services (While et al., 2004: 440). Many professionals in adult health services simply lack formal experience in transitional care (Shaw, Southwood, & McDonagh, 2004: 216). Others fail to appreciate the complexity of chronic health conditions, beyond their medical management (Sawyer et al., 1998). Many work in isolation from one another (Shaw et al., 2004: 216). Indeed, poor transition outcomes are frequently due to poor communication between paediatric and adult health services (Sawyer et al., 1998).

**Lack of Consultation** - The exclusion of young people and their parents or carers from the transition planning process is another common problem leading to an unsatisfactory or unsuccessful transition (Beresford, 2004; O'Sullivan, 2007: 2). '[Y]oung people without speech are particularly vulnerable to being excluded from the transition planning process' (Beresford, 2004: 583).

**Developmentally Inappropriate Services** - Another major hurdle is the ‘lack of health professionals with special training in the needs of adolescents’ (McDonagh et al., 2006; Sawyer & Bowes, 1999: 1132). Consequently, there is an overall lack of understanding and appreciation of the unique needs and issues of young people in both paediatric and adult health care sectors (Royal College of Nursing, 2004).

**Normative Tasks of Adolescence** - Transition can also be greatly affected by the normative tasks of the adolescent development phase, ie, the consolidation of identity, achievement of independence from parents, becoming part of a peer group and the establishment of adult relationships outside the family (Fiorentino et al., 1998; Hardoff & Chigier, 1991). For instance, there is often a tension between their transition from dependence to independence and the fact that their illness often keeps them tied physically, emotionally and financially to their families (Kyngas, Kroll, & Duffy, 2000: 379). Another example is the intensive ‘need to be normal’ and accepted by peers during this developmental phase which, along with typically rebellious behaviour, can result in non-adherence to medication and treatment (Desir & Seidman, 2003: 207; Jackson & Pencharz, 2003: 230; Kyngas et al., 2000: 380; Ullrich, Mattussek, Dressler, & Thon, 2002). Indeed, expectations of parents and healthcare professionals that a young person will increasingly be responsible for his or her own health care may be thwarted by ‘normal adolescent development, characterised by inconsistent behaviour, a sense of invulnerability, experimentation and the poor influence of future health outcomes on current behaviours’ (Sawyer & Bowes, 1999). Young adults are also more likely to experience other challenges to their psychosocial wellbeing, such as unemployment, depression, self-harm, STD, imprisonment or social disconnectedness and to experiment with substance abuse, including cigarette smoking and alcohol usage (Jackson & Pencharz, 2003: 230; Sawyer & Bowes, 1999). Thus it is clear that typical adolescent behaviours and psychosocial wellbeing can seriously affect the transition of adolescents with chronic health conditions. Yet, healthcare plans (if produced at all) often do not encompass broader aspects of planning for adult life (O’Sullivan, 2007: 3).

In short, the literature points to an overall lack of systems that promote a smooth transition from paediatric to adult health services (Fiorentino et al., 1998). Moreover, this absence of coordinated multidisciplinary transition care appears to be fairly widespread across high income countries (Sawyer et al., 1998).

### **3. Recommendations**

According to the literature a successful transition process needs to be:

**Planned** - Planning has been identified as a major factor in the success or failure of the transition process, second only to finance (Blum, 1995; Sawyer et al., 1998). Transitional planning needs to occur at the individual, organisational and inter-organisational level (Forbes et al., 2001). One way to ensure a planned, purposeful process (Brumfield & Lansbury, 2004: 223) is for health professionals, their patients and families to develop an individualised, written health-care transition plan. This should include details of what services are required, who should provide them and how they will be financed and be updated and reviewed annually or whenever there is a transfer of care (American Academy of Pediatrics, 2002; Shaw et al., 2004).

**Coordinated** - All health care services required by a person with a chronic condition need to be coordinated by a transition coordinator or case manager in partnership with the young person, their family and relevant health care professionals (American Academy of Pediatrics, 2002; Canobbio, 2001; Fiorentino et al., 1998; Myers, 2002; Sawyer et al., 1998).

In cases where the young person has a number of different problems requiring input from different consultant teams, there needs to be a clear decision as to who will coordinate the young person's care and provide a holistic overview and integration of their various treatment and management needs. It is important that the young person's view about whom is taken into account and negotiated (Department of Health, 2006: 23).

The coordinator can be one of many people, such as: a member of the specialist team, an occupational therapist, a general practitioner, a specialist transition nurse, a consultant in rehabilitation medicine or even jointly, for instance by a rehabilitation consultant and paediatrician. It is crucial to note that, whoever the coordinator is, they will need sufficient time to take on the task (Department of Health, 2006: 23). If of course, the particular health care delivery system allows or caters for this. Indeed, the administrative workload of these process issues, which has not been adequately recognised to date, is large due to the multidimensional and multidisciplinary nature of care provision, requiring effective communication (including written) between professionals (Robertson et al., 2006: 77). For instance, data capture upon transfer to adult services is vital to ensure transition efficacy and to enable argument for additional resources (Steinbeck et al., 2007). However, producing a multi-disciplinary summary of their history and management in a way that will be useful to someone taking over their care can take several hours in the case of a person with long-term conditions who has bulky medical records, though this does depend on the health care system and funding model (Department of Health, 2006: 24). Moreover, summarizing the information is not reimbursable for paediatricians and anecdotal evidence suggests the task is sometimes delegated to someone who does not have full knowledge of the patient (Steinbeck et al., 2007). One potential solution is fully electronic medical records, which facilitate and expedite the transfer of data between medical services, based on a template system to ensure uniformity and inclusion of essential information (Steinbeck et al., 2007).

**Collaborative** – Successful transition requires good communication, collaboration and coordination between young adults, their families, primary care specialists, sub-specialists and other health professionals (American Academy of Pediatrics, 2002; Department of Health, 2006; Shaw et al., 2004). However, it may be more difficult in practice than in theory for paediatric and adult health care providers to negotiate differences in culture, philosophy, practice and approach in order to facilitate the transition of a mutual patient (Rosen, 1995; Sloman, 2005). Moreover, if collaboration between adult and paediatric specialists continues beyond transition, the paediatrician can then stay informed of their ex-patient's progress through their adult life, as well as being a source of information for the adult specialist about the person's medical history (Warnes, 1995: 12). This then becomes an educational experience, as well as a collaborative one, for both specialists about the progression of the medical condition through the whole lifespan. It may also help to ease some of the anxiety paediatricians

may experience about the standard of care that the person they have known for all or most of that person's life will receive in the adult system. Other potentially positive outcomes of collaboration are the sharing of expertise, joint assessments, pooling of resources and sharing of workloads among different practitioners/agencies (Royal College of Nursing, 2004).

**Gradual** – The transition process is facilitated by a complex set of attitudes, skills and processes that are developed over time (Sawyer, Blair, & Bowes, 1997). As maturation typically takes about a decade, sometimes longer in people with chronic conditions or disabilities (Chamberlain & Rooney, 1996: 85), the process may continue over a number of years. Thus, one of the keys to a successful transition is for young people with chronic conditions to be prepared for transition steadily and gradually from an early age and transferred only after a long and adequate preparation (Myers, 2002; Soanes & Timmons, 2004; Vogel, Klaas, Lubicky, & Anderson, 1998). This includes making patients aware of differences in the practice philosophies and style between the paediatric and adult settings so they can anticipate a change in the style and content of service delivery as they move from one environment to the other (Rosen, 1995: 15). Transferring from paediatric to adult services can involve a change in location, staff, policies, advice, drug preferences and instructions (Cameron, 1985: 93). Thus they need to be equipped with knowledge and skills to allow them to interact effectively and assertively with their new adult health care providers (Robertson et al., 2006: 74). Increased self-determination needs to be encouraged within a timeframe that allows each step of the process to be carried out successfully before advancing to the next (Myers, 2002). It is crucial that families are also prepared to renegotiate their role in the adult health care system (Rosen, 1995: 15). Straddling the paediatric and adult systems should be discouraged to avoid mixed messages, splitting, or confusion over management plans (Rosen, 1995: 15). Nevertheless, the handover from paediatric to adult services should include a period of overlap in order to facilitate the building of a rapport between the young person, their parent/carer and their adult consultant (Fiorentino et al., 1998). Seeing a familiar face when they attend adult health services is important in order to reduce feelings of isolation and loneliness (Soanes & Timmons, 2004: 110). Numerous suggestions are made in the literature. One is to introduce young people to adult service staff early during the transition process, for instance by organising visits or orientation tours to the adult services before transition, if possible with a group of other adolescents from the paediatric unit (Miles et al., 2004: 311). Informal day or residential weekends are other suggestions (Soanes & Timmons, 2004). However rapport, trust and familiarity take time to build and young adults need to be supported through this period of adjustment (Visentin, 2003: 4). Thus, a more gradual approach may be necessary. One idea is to incorporate adult services staff into paediatric services (Miles et al., 2004). Another is to run transition clinics in partnership between the paediatric and adult services (Madge & Byron, 2002). A 'buddy' system has also been suggested as one way of helping young people traverse health care systems (Soanes & Timmons, 2004).

**Flexible, Responsive & Well-timed** – Transition should be well-timed and preceded by adequate groundwork (Rosen, 1995: 15). The concept of transition should be introduced as early as possible - long before it becomes an issue (Department of Health, 2006: 21). Timescales for transition should be flexible in content and timing, according to the specific personal needs of the individual (Brumfield & Lansbury, 2004: 233; Chamberlain & Rooney, 1996). For instance, time

elapsed since the end of a treatment or operation 'may be important in some situations and transition should, where possible, be during remission rather than relapse or when disease is active' (Department of Health, 2006: 20). Nor should transition occur arbitrarily at a certain age but be determined individually, depending on the physical, psychological, intellectual, developmental and social maturity of the person and after discussion with them and their family (Cameron, 1985; Myers, 2002; Salmi et al., 1986; Soanes & Timmons, 2004). 'The actual transfer of care should be timed to coincide with generally increasing autonomy but health care transition does not occur at a point in time; it is a process that occurs over time' (Rosen, 1995: 15). In the case of some young people with intellectual disabilities this is not always possible. Though there is no simple tool to assess readiness to function in the adult sector, they should: be able to communicate independently with health care providers and advocate forcefully on their own behalf; have already assumed substantial responsibility for their own management; and have demonstrated themselves as effective in their own self-care (Rosen, 1995: 15). One way to monitor this is through checklists and evidence records for key areas such as: self-advocacy; independent health care behaviour; sexual health; psychosocial support; educational and vocational planning and health/lifestyle (Royal College of Nursing, 2004). 'Initiatives such as out-of-hours clinics, age-specific clinics, self-medication, self-care and 'parent-free' consultations can help young people begin to take responsibility for their own health care needs' (Royal College of Nursing, 2004).

**Individualised** – Due to the heterogeneity of young people with chronic health conditions (not to mention the large range of conditions), there can be no "one-size-fits-all" solution or universal transition prescription (Rosen, 1995: 14). 'There are several models for good transition... Different approaches may be needed for different types of conditions according to their prevalence and the ways in which specialist health care is organised' (Department of Health, 2006: 12). Thus the transition process should be 'individualized to meet the specific needs of each adolescent, his or her family, the old and new providers, and the system in which they find themselves' (Rosen, 1995: 14).

**Person-centered** - Young people with chronic conditions should take a central role in the decision-making and planning of the transition process (Beresford, 2004). Transition may be difficult for many reasons, including the likelihood that they have developed a dependent relationship on their parents for their daily medical care needs (Nasr, Campbell, & Howatt, 1992: 684). Thus, health professionals 'need to work with the adolescent to develop skills for managing their condition more independently' (Miles et al., 2004: 312). In particular, it is important to enable young adults to influence and direct change in their own lives (Dee & Byers, 2003). For some, family involvement remains necessary throughout adulthood because of the nature or severity of their condition or disability (Bennett et al., 2005: 373). For others, however, continued (rather than initial) family involvement can be embarrassing or negate the purpose of transition, as adolescents at this age are often trying to establish their own identity as adults, separate from their parents (Soanes & Timmons, 2004: 109). This is not to deny the importance of families throughout the transition period, the extent of which is dependent on the cultural emphasis placed on family life by those being cared for (Miles et al., 2004). They need to be involved, supported and treated with sensitivity throughout transition. Health practitioners need to balance guiding young people with chronic conditions towards self-management of their healthcare needs

with ‘respect for the family’s strengths and autonomy, and their role as active partners in their child’s care’ (Pownceby, Ratcliffe, Abbott, & Kent, 1997: 38). For the purposes of this review, the term *self-management* refers to the management of a chronic health condition through: problem solving, decision making, resource utilization, the formation of a patient-provider partnership, action planning and self-tailoring (Lorig & Holman, 2003). One suggestion is to have a transition period where parents do not attend all the appointments in the paediatric clinic (Visentin, 2003: 3). Confidentiality and privacy are paramount in the care of adolescents and ‘young people should be given information on their rights, including consent and confidentiality as well as effective ways of dealing with a variety of medical situations’ (Department of Health, 2006: 22). However, in the case of young people with intellectual disabilities, ‘the health professional may have to balance the individual’s ability to understand with his or her right to privacy and confidentiality’ (Department of Health, 2006: 31).

**Empowering** – A transition process should help young people with chronic health conditions to develop communication, decision-making, assertiveness, advocacy and self-care skills (Robertson et al., 2006: 74). In doing so, it should empower them to take responsibility for their own health and make informed choices and decisions regarding their emotional and social development, and health and wellbeing both now and in the future (Department of Health, 2006: 5). This includes ‘skills in managing social, educational and employment opportunities and challenges and in developing the independent living skills which underpin fulfillment and wellbeing (Department of Health, 2006: 15).

**Smooth, Consistent & Well-Managed** – A smooth transfer requires good medical management, for instance the preparation and maintenance of a portable, accessible and up-to-date medical summary of the young person with a chronic health condition. This is particularly important for young people with intellectual disability. Once transferred to adult services, continuity with a particular doctor or other health professional is vital (Dovey-Pearce, Hurrell, May, Walker, & Doherty, 2005; Miles et al., 2004: 311). Administrative support needs to be negotiated and formalised at both ends of the medical transfer because casual agreements between doctors are prone to failure (Department of Health, 2006: 24). Policies and transition protocols need to be agreed and receive management support (Department of Health, 2006: 24).

**Educational/Informative** – Developmentally appropriate patient-education about their condition and about adherence to medications is also important (Kyngas et al., 2000). This is particularly the case just after being transferred from paediatric care because often young adults know very little about their condition due to their parents having assumed all responsibility for their care in the past (Warnes, 1995: 13). One study of adolescents with congenital heart disease found that between 30% and 40% of young adults remain uninformed about their defects and about what follow-up care is required (Canobbio, 2001: 368). One suggestion is to encourage young people with chronic conditions to become “experts” in their own condition and, in some cases, to contribute to the education of healthcare staff and to service improvement’ (Department of Health, 2006: 18). Non-adherence to prescribed medication and activity limitations in young adults becoming increasingly responsible for their own health care is less likely in those who have been provided more education about their condition (Canobbio, 2001).

**Supportive & Positive** - Young adults need sensitive and non-intrusive support, encouragement and positive feedback, throughout their transfer from paediatric to adult health care services as they strive to manage their chronic illness and normal developmental crises (Kyngas et al., 2000: 386; Pownceby et al., 1997; Visentin, 2003: 3) and in order to reach their physical, social and psychological potential (Beresford, 2004: 581-2). Throughout transition preparation it should be made clear to the young person that there is a positive, purposeful future ahead (Cowlard, 2003: 39).

**Developmentally appropriate** – Ideally, services into which young adults transfer need to be ‘developmentally appropriate health care supported by psychosocial services... in dedicated adolescent facilities’ (Bennett et al., 2005: 373). Indeed, health services specifically geared to adolescents and/or to transition to adulthood are recommended throughout the literature (Morris, 1999). Health professionals require different consultation skills from those needed for children or adults in addition to the technical knowledge relevant to each individual specialty (Department of Health, 2006: 31). They need to be well informed about generic teenage health issues such as skin problems, worries about weight, normal puberty and sexuality - for example, drug interactions relevant to contraception’ (Department of Health, 2006: 31). They also need to understand the normative tasks and specific psychosocial issues and needs of adolescence in order to provide support that takes into account how the health care goals of young adults fits with their other life-goals (Dovey-Pearce et al., 2005: 410). For instance, they need to be able to provide adolescents with information regarding issues such as fertility, pregnancy, contraception, safe sex, cross-infection, further education/employment and smoking/substance abuse (Cowlard, 2003: 41). However, due to limited training opportunities in adolescent health in the UK and elsewhere, there is a general shortage of adolescent friendly health services staff by professionals who understand and are trained to look after them (McDonagh et al., 2006: 201). Given anecdotal evidence that it only takes one youth-friendly health professional in an adult team to enhance the capacity of that whole team’s approach to young people (Steinbeck et al., 2007), educating medical, nursing and allied health professionals in adolescent health may be a crucial aspect of improving transition services. One suggestion is to make the core knowledge and skills required to provide developmentally appropriate health care transition services to young people with special care needs part of the training and certification requirements for primary care residents and physicians in practice (American Academy of Pediatrics, 2002: 1305). Another is for ongoing professional development and training of health professionals:

Professionals may need to consider further development of their knowledge and skills in working with young people, including: the biology and psychology of adolescence; communication and consultation strategies; multi-disciplinary and multi-agency teamwork; and an understanding of the relevant individual conditions and disorders and their evolution and consequences in adult life (Department of Health, 2006: 13).

A developmentally-appropriate service also requires an environment that engenders a sense of adulthood but, at the same time, is a specific young person’s environment (Department of Health, 2005; 2006: 18; Miles et al., 2004). It also needs to involve young people in service design and delivery by providing opportunities for young people to ask questions, express opinions and make decisions (Department of Health,

2006: 19).

**Holistic & Comprehensive** – A study of adults with spinal cord injuries concluded that their greatest opportunity for a satisfying adult life was not significantly related to neurological level of injury but rather that their rehabilitation emphasized psychosocial factors such as education, employment, recreation, socialisation and long-term health management (Vogel et al., 1998). Indeed, what adolescents most want in adulthood—friendships, a social life, work and independent housing—are not independent of each other, and most cannot be fully achieved through the provision of a single agency (Beresford, 2004: 585). Thus transition must allow for the fact that adolescents are undergoing changes far broader than just their clinical needs (Royal College of Nursing, 2004). Moreover health professionals often need to contribute to the development of the long term plans for education, employment and social support in a variety of ways, depending on the young person's disability. For example, they may need to advocate as part of negotiations for housing modifications or funding or provide information and interpretation on the natural history of the disorder and the likelihood of improvement or deterioration, the treatment options and the risks of various courses of action (Department of Health, 2006: 29-32). Therefore the health-care sector cannot work in isolation from other professionals and networks that impact the lives of young people - a multi-agency approach is essential. A smooth transition should involve education, vocational training, employment, youth and social services, transport, housing, health services and recreation (American Academy of Pediatrics, 2002; Cowlard, 2003; Department of Health, 2006; Social Care Institute for Excellence, 2005). There are examples of co-operation between a wide range of professionals and organisations in the UK in the development of transitions services' (Department of Health, 2006: 37). Health professionals should also keep young adults and their families informed about community-based resources which could complement the role of the family, extend their networks and help them during those difficult years of transition (Pownceby et al., 1997: 38; Vogel et al., 1998: 1502). These might include, for instance, resources that provide vocational rehabilitation, independent living education, sexuality education programs and other life skills (Hardoff & Chigier, 1991).

**Non-discriminatory** – Health services and professionals need to allow for specific problems that make consultation with a person with a disability more demanding and time-consuming, such as difficulties with communication due to hearing or speech disorders, inability to explain symptoms clearly because of intellectual impairment or being unable to undress quickly for physical examination (Department of Health, 2006: 31). Other factors which intersect with and affect transition planning and outcomes include: homelessness; domestic violence, family conflict and/or family breakdown; sexual abuse; parents with mental health problems, drinking or substance misuse problems; unemployment; teenage pregnancy and parenthood; school expulsion or truancy and, in some cases, coming from an ethnic, aboriginal or refugee background (Department of Health, 2006: 34). Though considered important, very little attention is paid to these issues in the transition literature.

**Monitored & Evaluated** – Finally, each stage of transition should be carefully monitored 'to allow timely troubleshooting of logistic problems and early detection of serious difficulties' (Rosen, 1995: 15). Monitoring should continue until the young person is established in the adult service (Department of Health, 2006: 12). Given the

lack of high quality primary material on what works and what does not work in practice (While et al., 2004: 451)}. Transition processes should also be comprehensively evaluated (Bennett et al., 2005: 374; Forbes et al., 2001). Thus, those who have developed new services that are running well should share their research, protocols and ideas (Cowlard, 2003: 41)

#### **4. Evaluations of Transition Programs**

Many of the above recommendations are based either upon studies which identify service gaps/inadequacies or upon anecdote and experience rather than on hard evidence about 'what works' (Bennett et al., 2005; Beresford, 2004; Fiorentino et al., 1998; Miles et al., 2004). In some cases new transition services have been developed and run without formal evaluations, thus their positive reports of successful transition services are yet to be verified (Chamberlain & Rooney, 1996). One review which identified over 5,000 publications on transition from child to adult care (generally, rather than of young people with chronic conditions specifically), appraised 368 to find only 126 of these described transitional care practice and, of these, only three used an explicit methodology to guide an evaluation, survey/interview or review to generate evidence (While et al., 2004: 442).

The evidence-based movement (closely linked with the Cochrane Collaboration, whose aim is to promote and foster an evidence-based approach to research and practice) within the health sciences has been criticised for reproducing the exclusion of other forms of research, particularly more qualitative forms (Holmes, Murray, Perron, & Rail, 2006). Undoubtedly the need for in-depth, qualitative research remains (Petticrew & Roberts, 2003) and, in the case of transition, particularly the need to elicit the views and experiences of adolescents with chronic conditions themselves. At the same time, without an evidence base (ie randomised controlled trials, clinical trials, cohort studies and/or meta-analysis, the systematic review of a series of trials) with which to support or refute current practice and to evaluate different models of clinical care, it is hard to justify health service development in this area to health funders (Sawyer & Bowes, 1999: 1133). 'Indeed, the paucity of robust evidence is a major impediment to the development of services founded upon tested interventions and service models (While et al., 2004: 452).

Thus, like many similar reviews of the transition literature (Department of Health, 2006; McDonagh, 2006; While et al., 2004), only a handful of evaluations are reviewed here and, it should be noted that the findings may not be generalisable cross-nationally or even regionally, as they are often largely dependent on local structural issues.

One of the first studies to evaluate an already existing transition program, in this case of young people with cystic fibrosis in the US, concluded that actions to facilitate transition include: the incorporation of adult-care specialists in the center program, the establishment of inpatient services in internal medicine wards and the creation of transition teams and parallel adult-care teams (Nasr et al., 1992: 684).

As many have pointed out, there can be no single ideal transition model, nevertheless, as one English study found, young people with physical disabilities that have access to a multidisciplinary specialist team developed specifically to facilitate transition from

childhood to adulthood are more likely to participate in society than those who use *ad hoc* health services (Bent et al., 2002). Moreover the cost of specialist transition services were no more expensive than *ad hoc* services, which may serve to allay common concerns about the cost-effectiveness of health care services (Bent et al., 2002).

A more recent Australian project involved the successful transfer of 11 young adults with either spina bifida or cerebral palsy from a children's hospital to one of two participating adult hospitals (Sloman, 2005). The project was based on the establishment of two clinics that piloted transition models, the process of which was documented. Indeed a report describing the project provides an extremely practical and detailed account of the sustainable, routine processes, protocols and relationships used to facilitate transition during the project. Broadly, three key features of success were identified. 1. Many staff working in new areas, with new patient groups, embracing new ideas and new ways of working, thus involving all the elements of a change management process and depending for its success on the support and leadership of key people/positions within the participating Health Services. While this created some barriers, goodwill and leadership enabled these barriers to be overcome. 2. A combination of executive level support and medical leadership at all three hospitals. 3. A designated project worker (Clinic Coordinator) at each site, with *adequate time* allocated to the project and a Transition Project Officer at the children's hospital (Sloman, 2005: 18). Other outcomes include: an increase from one transition clinic in January 2005 to 10 transition clinics in December 2006; a 30% reduction in 'over-age' inpatient (> 20 years) attendances at the children's hospital between January 2004 and December 2006 and a 24% reduction in over-age outpatient attendances between January 2004 and December 2006 for the same age group (Steinbeck et al., 2007).

Another recent Australian study evaluated a transition program for adolescents with cystic fibrosis (Craig, Towns, & Bibby, 2007). The program involves a 'Preparation Phase' in early adolescence that encourages attendance at the adolescent CF clinic, education, promotion of self-management skills and assessment of general health and psychosocial issues. This is followed by an 'Active Phase' beginning at around sixteen years of age, with eventual transition to adult care at around eighteen years of age. The goals of this phase include encouragement of attendance at adolescent CF clinic, optimization of self-management skills, introduction and orientation to adult health services, adult physicians and team members, negotiation of an initial appointment at the adult clinic and liaison between adult and paediatric teams and the primary health care general practitioner. Findings were based on a self-administered questionnaire completed by a group of 'pre-transition' adolescents and their parents who had not moved on to adult health care and a 'post-transition' group who had moved on from a Sydney children's hospital over a six year period. The questionnaire examined patient and parent concerns about adult health care, participation in steps of the transition process, satisfaction with transition and health related quality of life. Measures of the severity of their condition (lung function tests and body mass index) were also included. The evaluation concluded that:

- parents had more concerns than young people in the pre-transition group

- no evidence that patients and their parents experienced fewer concerns about transition after completing the transition process, suggesting that it may take a long time in the new adult system before a patient is able to feel comfortable.
- most people were satisfied with the transition program, those participating in more steps of the program experiencing more satisfaction with the transition process.
- two of the most useful steps were meeting the adult physicians and visiting the adult hospital but these were the least frequently attended steps of the program.
- no evidence of a relationship between participation in steps of the transition program and measures of the severity of their condition or quality of life.

This study only examined a small (n=137) cross-section of young people with cystic fibrosis. Another limitation was that the pre-transition and post-transition groups were not identical, nor matched for age, gender or severity of condition and may not be representative of the entire population. One of the methodological problems of the study was the use of questionnaires that relied on post-transition patients and families to remember the steps of transition that were completed rather than as they were completed. Future research could take a longitudinal approach to examine how concerns change over the course of transition.

Another study, based on an audit of a new transition service started up in a London hospital in 2000, was less successful (Cowlard, 2003). Subsequent to the transfer process of children with cystic fibrosis from paediatric to adult care services at that hospital being identified as in need of review, a new system was introduced which offered families joint transition consultations with paediatric and adult cystic fibrosis care teams. The formal handover appointment was conducted in the paediatric outpatient department, with both paediatric and adult teams present. Patients were able to meet formally with the medical staff and then informally with the adult cystic fibrosis nurse consultant, dietician and physiotherapist. The essence of the joint consultation was to introduce patients to the new team in an environment with which they are already familiar. The young person was guided through the process by one of the paediatric cystic fibrosis nurses, who also gave the family the opportunity to visit the inpatient ward and day case unit and meet the adult cystic fibrosis team again. The two cystic fibrosis nurses, one from each team, jointly wrote a standard for transition, the aim of which was to ensure that the transition from paediatric to adult care is a planned, collaborative process involving the young person, family and professional caregivers, and considering all patients' physical, psychological, social and cultural needs. An audit of the transition clinic system was conducted in 2002 from the perspectives of professionals, patients and caregivers, showing an overall improvement in the transfer process. However it also indicated that the information given to all families verbally and in a written information pack at the time of transfer was not clearly remembered and that the move was still very stressful for patients and their families. Thus, it was concluded that further service development was required to cater for the challenges and individual needs of adolescents. To this end, the service is again under review and separate transfer clinics are being trialled (Cowlard, 2003).

Research into another British transitional care programme also reported mixed results (Robertson et al., 2006). The study is based on a retrospective case note audit of recent patients with juvenile idiopathic arthritis transferred to adult centred rheumatology care in 10 participating UK paediatric rheumatology centres before and 12 to 24 months after the implementation of a structured coordinated programme of transitional

care. Data collected included demographic details, age when transition was first discussed, when transfer occurred, transitional care components, documentation of transitional issues and needs, multidisciplinary team involvement and details about the adult rheumatology service involved. Comparisons were made between the baseline and follow up data for actual data values where applicable and the documentation of information in the medical notes. The age at which the concept of an independent clinic visit was introduced decreased from a mean of 16.8 to 15.8 but there were no other changes in age related transitional milestones. There were improvements at follow up in documentation of transitional issues, condition specific educational needs, adolescent readiness and parental needs. Significantly more participants had preparatory visits to the adult clinic and a transition plan. However, no difference was observed between project participants and others in: a) transitional care components such as preparatory visits to adult clinics, addressing condition specific educational needs; b) discussion of certain specific transitional issues such as home relationships, career plans, education, diet, exercise, social activities, alcohol, drugs, driving, dental care, sexual health, sleep and future independent use of health services c) documentation of patients phoning with own queries. An improvement in documentation suggests that the research project had an immediate impact on clinical practice and increased awareness of transitional issues beyond research participants. However, there was a discrepancy between documentation and actually translating policy into practice. Possible reasons for this include lack of training in this area for health professionals, inadequate numbers of health professional staff and lack of administrative support. It was concluded that there was room for improvement in the transition programme, particularly at the paediatric/adult interface.

In Australia the New South Wales Department of Health's Greater Metropolitan Clinical Taskforce (GMCT) Transition Care Program for Young People with Chronic Illness and Disability Arising in Childhood recently conducted a study of the patient data of over four thousand young people in tertiary paediatric hospitals (Steinbeck, Brodie, & Towns, accepted). The study was based on data collected between August 2004 and October 2005 by face-to-face interviews with a minimum of two health professionals from each specialist service. Each department was asked about: 1) total numbers of young people 12 years and older; 2) the numbers of adolescents over the age of 12 years who were in the 'preparation for transition group'; 3) the number of adolescents expected to transition to adult care per annum; 4) any specific transition practices already in place; and 5) whether they routinely determined that the transitioning young person had accessed the adult service. The study identified diabetes, endocrinology, neurology (excluding cerebral palsy and developmental disability), spina bifida and gastroenterology as the five most prevalent conditions requiring specialist to specialist transition. It found that, despite large numbers of adolescents with chronic illness transitioning annually, there are significant gaps in information on these adolescents with regard to data collection and management, and transition protocols. For instance, it was not routine for paediatric services to contact the adult service to which they were referring prior to transition. Also, current data collection techniques on adolescents requiring transition in paediatric services were found to be likely to limit their ability to strategically plan transition. For instance, though 95% of paediatric services kept a database, less than half was electronic, which made retrieval of patient numbers difficult. It was concluded that several aspects of the transition process require attention including co-ordinated data collection and uniform transition procedures. In addition the numbers of young people requiring

transition mean that adult health care also need to engage in the process of transition.

### **Professional Training in Adolescent Healthcare and/or Transition**

There is a great deal of agreement amongst researchers regarding the problematic aspects of transition and, in many respects, the transition literature is preaching to the converted. As the literature indicates, there is much less awareness and consensus on the topic in everyday healthcare practice, particularly in adult services, and this is a major underlying problem. Thus, a small number of transition researchers have begun to study the effects of training or education in adolescent health and/or transition on health practitioners.

An Australian randomised controlled trial focusing on the training of medical professionals rather than on the transition of adolescents, evaluated the effectiveness of an educational intervention in adolescent health designed for general practitioners (Sanci et al., 2000). Self-selected general practitioners (n=103) from metropolitan communities completed a multifaceted educational programme for 2.5 hours a week over six weeks on the principles of adolescent health care followed six weeks later by a two hour session of case discussion and debriefing. The programme covered adolescent development, consultation and communication skills, health risk screening, health promotion, risk assessment of depression and suicide and issues in management of psychosocial health risk including interdisciplinary approaches to care. Evaluation of the programme consisted of: objective ratings of consultations with standardised adolescent patients; questionnaires completed by the general practitioners to measure their knowledge, skill, and self perceived competency, satisfaction with the programme and self reported change in practice; and baseline testing and follow up at 7 and 13 months. The intervention group showed significantly greater improvements in all outcomes than the control group at the seven month follow up except for the rapport and satisfaction rating by the standardised patients. Doctors completing the training had substantial gains in knowledge, clinical skills and self perceived competency than the controls; these gains were sustained at 12 months and were further improved in the objective measure of clinical competence in conducting a psychosocial interview. At the 13-month follow up most improvements were sustained, the confidentiality rating by the standardised patients decreased slightly and the objective assessment of competence further improved. Almost all (98%) the participants reported a change in practice attributable to the intervention. Thus it was concluded that i) general practitioners are willing to complete continuing medical education in adolescent health care and ii) the design of the intervention using evidence based educational strategies proved an effective and quick way to achieve sustainable and large improvements in knowledge, skill and self perceived competency. A 5-year follow-up of this study indicated that improvements were sustained in all measures from 12 months to 5 years after the intervention in those participating in the second study, ie 85% of the original intervention group (Sanci, Coffey, Patton, & Bowes, 2005). Furthermore, over half (54%) reported receiving further training in related areas over those 5 years, though this did not improve sustainability. A total of 98% reported maintaining their clinical approach to youth and 46% reported maintaining practices to address systemic barriers to adolescent health care access. Obviously, self-reporting has limitations and drawbacks as a method of data collection.

Another course evaluation is of a one- week course for third and fourth year medical students in an American university that addresses the transition for youth with special health care needs, using cystic fibrosis as a model and emphasizing patient and family-centered care, cultural competence and decision making in end-of-life issues (Hagood, Lenker, & Thrasher, 2005). The course content included required readings, seminars, group and panel discussions, as well as attendance at two cystic fibrosis outpatient clinics (one each in pediatric and adult settings), and interviews of a young adult with cystic fibrosis and one family care-giver of a teenager with cystic fibrosis. Although there are not yet clear objective criteria for evaluating the impact of such a course, the participants have generally reported very positive experiences, appreciating the chance to see illness from the patient and family perspective and to interact candidly with young people and family members regarding non-medical aspects of their condition. Post-course questionnaires indicate that students were particularly affected by the patient and family member interviews, the interdisciplinary panel discussions and the discussions regarding health care financing. Students taking the course have gone on to residencies in pediatrics, family practice, internal medicine and radiology.

More interestingly, for the purposes of this review, there were also several unintentional outcomes of the course. For instance, for the researchers who developed the course, it fostered discussions and generated specific ideas to improve the transition process at their institution, improved communication between the adult and pediatric cystic fibrosis teams and helped each team to gain an understanding of the other's struggles and frustrations with the transition process. Consequently, those teams now meet quarterly to discuss transition issues and communicate much more frequently on an informal basis as needs arise. The course also highlighted the need for, and importance of, patient and parent input and involvement, prompting them to develop a patient-parent advisory committee as a forum for obtaining their input with ongoing changes and quality improvement initiatives within the cystic fibrosis center. Also, panelists participating in the course have benefited from the interdisciplinary discussions and have found that the course has clarified important concepts in planning transitional care at their institution that can be incorporated immediately. Patients and family members felt they were making a valuable contribution to the education of future physicians.

## **5. Current Gaps in Our Knowledge**

Much of the literature reflects what health practitioners define as successful transition. From the medical perspective, very often the 'ultimate goal of transition to adult health care services is to facilitate the development of successful self-management in young people with chronic conditions' (Royal Australasian College of Physicians, 2007). However, there are also numerous studies of transition based on the perspectives of young people with chronic conditions (for example, Bent et al., 2002; Brumfield & Lansbury, 2004; Dovey-Pearce et al., 2005; Fiorentino et al., 1998; Miles et al., 2004; Soanes & Timmons, 2004; Ullrich et al., 2002; Visentin, 2003). Though it may not be the case in practice, in the literature at least, there is a great deal of consensus between both practitioners and adolescents in regard to what is needed for successful transition. This is not surprising however, given the literature is dominated by practitioners and researchers either practising or advocating "adolescent friendly health care services" (McDonagh & Viner, 2006).

Another reason for the great deal of consensus within the literature is the focus on generic elements of transition in isolation from contextual factors and influences, such as the operation of national, state or local funding arrangements, health policies and/or systems. For instance, many of the specific ‘solutions’ summarised above tend to be based on the notion that the problem is primarily one of knowledge and/or attitudes rather than the structural characteristics of services and the competing influences of different drivers on organisational performance. Given that at least some of the recommendations above would be specific to certain types of health care delivery systems and certain types of chronic conditions, it seems fruitless to continue making broad generalisations and looking for universal models of service delivery.

Indeed, there is general agreement throughout the transition literature on the need for further evaluation of specific transition programs. Most of the literature about transition to adulthood published in the past decade is descriptive or conceptual in nature and, although the number of studies of transition services is slowly increasing, very little evidence is available about the effectiveness of specific models of transition (Stewart et al., 2007: 1). Thus, many researchers have bemoaned the general ‘paucity of high-quality primary research in practice settings’ (Forbes et al., 2001). This includes, but is by no means limited to, the lack of:

- long-term follow-ups of the transition process, both child to adult services and childhood to adulthood (Beresford, 2004: 586).
- evaluations of practice and models of service delivery (Beresford, 2004: 586).
- evaluations from the perspective of young people with chronic conditions, their parents and clinicians (Craig et al., 2007).
- better understanding of the needs and perspectives of young people with chronic health conditions entering adult healthcare and of the gaps in these services (Steinbeck et al., 2007).
- examinations of health outcomes and cost–benefit issues (Bennett et al., 2005: 374).
- examinations of specific factors which contribute to a successful transition process. This could include individual patient, clinician and systemic factors (Craig et al., 2007).
- clinical audit projects of the medical consequences for young people on making the transition to adult health services (Department of Health, 2006: 36).
- assessments of whether young Australians with chronic conditions in an urban setting who are able to access tertiary centres have different transition outcomes compared to their rural counterparts (Craig et al., 2007).
- the effect of other complex and challenging aspects of rural and remote health on transition (Steinbeck et al., 2007).

- more reliability and validity testing of instruments to help develop the best tools to evaluate transition programs (Craig et al., 2007).
- data collection on numbers of young people with chronic illness who are transitioning (Steinbeck et al., 2007).
- evidence to inform how best to overcome cultural differences between paediatric and adult services in order for adult services to fully engage in the transition process (Steinbeck et al., 2007).

The above review is not intended to provide detailed critical analysis but an overview of the current state of the literature on the transition between paediatric and adult health services for adolescents with chronic health conditions. It focuses on mainstream transition literature and does not include research on the transition experiences of specific groups such as blind, deaf, intellectually disabled, homeless, CALD or indigenous adolescents with chronic health conditions. Nor does it consider location-specific contextual factors of transition, such as the political, economic, national, local, structural, organisational and other social or health system contexts. Given the size of this body of work, literature searches upon which this overview is based were not exhaustive. However the review was subjected to examination by [number] members of the “[name]” collaboration who have expertise in transition issue, and [number] other transition experts, who provided detailed feedback which was incorporated into the review. Thus we believe that it represents a fair description of the field of study.

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