

Growing Up Ready for Emerging Adulthood

An evidence base for professionals involved in transitional care for young people with chronic illness and/or disabilities

*“We cannot always build the future for our youth
but we can build our youth for the future”*

Franklin D Roosevelt 1882-1945

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This document is based on a presentation given by the author at a major national conference on the 23rd March 2006 convened by the Department of Health, the Royal Colleges and the Department for Skills and Education. The aim of the conference was to raise awareness of this area and empower existing local champions of transition to support further development of this vital and important area with respect to clinical service provision, education and training in addition to research.

1. INTRODUCTION

Transitional care is a key element of adolescent health care irrespective of the presence or absence of chronic illness and/or disability. ALL young people will hopefully make the transition from childhood to adulthood and along the way, move from the family home to live independently, from school to further education and/or training and/or work. Another transition they will make is that from paediatric to adult services including health care. Many young people make these transitions, including the latter, successfully. Some however will find them difficult for various reasons and this latter group potentially includes those young people with chronic illnesses and/or disabilities.

Although there are many compelling arguments that something needs to be done about transitional care service provision in the UK [1-4], many practitioners and policymakers are unsure as to what should be done and/or how to implement such changes in practice. **Transition is indeed, “discussed frequently.... (but) studied rarely”**[5]. To date there have been no true randomised control trials with the majority of studies being descriptive (35%) or based on user accounts (34%) with only 14% being true evaluations of services [6]. In an important multimethod review commissioned by the National Coordinating Centre for NHS Service Delivery and Organisation R&D, While et al stated that “overall, the strength of the evidence...was fairly weak” and that there remains a “paucity of robust evidence” [6]. A further review published at the same time echoed these findings [7].

This document will attempt to complement these reviews with a summary of the key evidence published since in addition to evidence from a broader context, which supports individual components of transition [Table 1]. The aim of the paper is to provide a resource which can both support practitioners in future business case planning and service developments in addition to encouraging clinical researchers to study this fascinating and challenging area.

Table 1
Summary of Evidence for Transitional Services

Evidence of Need

- Increasing recognition
- Experience of young people
- Increasing numbers
- Loss to and lack of follow-up post transfer
- Current limited service provision
- Differences between paediatric and adult services
- Potential for delayed adolescent development into young adulthood

Evidence of Process

- Transition models
- Transition programmes
- Planning
- Timing
- Skills training
- Transition for Parents
- Multidisciplinary and multiagency approach
- Information transfer
- Importance of place and environment
- Involvement of young people in service development

Evidence of Barriers

- Time

- Training
- Money
- Different perspectives

Evidence of Outcomes

2. TRANSITION: A STAGE – NOT AN AGE!

Before going further however, a few definitions will be clarified for the reader.

2.1 *Transition vs. Transfer*

Transition has been defined as “**a multi-faceted, active process that attends to the medical, psychosocial and educational/vocational needs of adolescents as they move from child to adult centred care**” [8]. The key principles are summarised in table 2. Transition should be conceived as a dynamic process with a beginning, middle and end [9]. The beginning is when the decision to begin or prepare for transition is made, usually within paediatric care. The middle phase is that of transition readiness when the adolescent, their family and the providers are prepared to begin, continue and finish the process of transition. The final or end stage occurs when the adolescent or young adult not only transfers to adult care but is actively participating in adult care activities e.g. of self-management and decision making [9]. Transfer is therefore only an event within the process of transition.

Table 2
Key Principles of Transition

An active, future-focussed process

Young person centred

Inclusive of parents/care-givers

Starts early

Resilience framework

Multidisciplinary, inter-agency

Involves paediatric and adult services in addition to primary care

Provision of co-ordinated, uninterrupted health care

- age and developmentally appropriate
- culturally appropriate
- comprehensive, flexible, responsive
- holistic –medical, psychosocial and educational/vocational aspects

Skills training for the young person in communication, decision-making, assertiveness, self-care and self-management

Enhance sense of control and interdependence in health care

To maximise life-long functioning and potential

2.2 *Age Criteria*

A useful phrase for practitioners in transitional care is that adolescence is a “**stage not an age**”!! Unfortunately the lack of consensus with respect to age criteria between providers and/or between policy makers only helps to confuse area even further. Although the National Service Framework for children, young people and maternity services (NSF) [10,11], Children’s Trusts [12] and the Connexions strategy [13] address the needs of young people up to the age of 19 years, many paediatric services have a 16 year old cut off criteria, often in the absence of age and developmentally appropriate adolescent health services to undertake the care of the 16-19 year old age group. Other policy documents however have considered this age group and found them wanting! [14]. A disproportionate prevalence of disadvantage is reported in the 16-25 year old age group [14], the age band within which many of the transitions described above are likely to take place. Reassuringly, the definition of youth by

both the European Union [15] and the World Health Organisation [16] include the “invisible early twenties” [14]. There have been recent calls from psychologists to recognise this stage as another stage of adolescent development – that of “**emerging adulthood**” particularly in the light of the sociocultural shifts which serve to delay many of the normal adolescent transitions [17,18]. This period of late adolescence and young adulthood too often is at risk of becoming a twilight zone with young people falling out of paediatrics but not yet falling into adult medicine. In this document the term young person or adolescent will refer to 10-19 year olds and the term young adults to incorporate late adolescence and the early twenties i.e. up to the age of 25 years.

3. EVIDENCE OF NEED

3.1 Increasing Recognition

The specific health needs of adolescents have been recognised for many years in the UK [19-23] and have received significant impetus recently with the publication of the hospital standards of the Children’s NSF in 2003 [10] and subsequently in core standard 4 of the complete NSF published a year later in 2004 [11]. The “You’re Welcome” quality standards for adolescent health services published in 2005 provide a useful framework for both audit of current services and development of new services [25]. Health is also an integral component of other important documents published by education [12,13], the social exclusion unit [14] and the youth service [26,27]. In addition to these national documents, other major documents were published by professional bodies in the UK [28-30] echoing reports from our North American counterparts [31] and the World Health Organisation [16]. A summary of these documents are listed in table 3

Table 3

Major Policy and Consensus Statements of Relevance to Transition and Adolescent Health

Government

National Service Framework for children, young people and maternity services [10,11]
Every Child Matters [12]
Choosing health [32]
Our Health, Our Care, Our Say [33]
You’re welcome [25]
Youth Matters [26,27]
Transitions: Young adults with Complex needs [14]

Professional Bodies

Royal Colleges
- Getting it Right for teenagers in your practice (RCN & RCGP) [28]
- Adolescent Transition: Guidance for nursing staff (RCN) [29]
- Bridging the Gap: Health Care for Adolescents (RCPCH) [30]
British Medical Association
- Adolescent health [31]

International

American Academy of Pediatrics [32]
Canadian Paediatric Society [35]

3.2 Experience of young people

The evidence of need from young people and their parents is very persuasive on the need to improve transition [6,7]. Transitional care research now needs to move on from the stage of needs assessment to evaluation of services to meet these needs so only examples of the key

areas of evidence will be given here and interested readers are referred back to the reviews for further details [6,7].

- Young people with a range of conditions have expressed **concerns regarding transfer** [36-46]. Those who have been transferred have described the event of transfer with words such as “*dumped...abandoned...thrown out....cut off....tossed out....sudden....lost in the shuffle...hurtling into a void*” [36, 42, 45].
- However, although young people may be reluctant to transfer to adult care, they have also been reported to **favour changes towards more adult-orientated care** during adolescence [43,44].
- There is evidence from several UK based studies, summarised in [7] that **quality of medical care of young people with physical disabilities declines after transfer** to adult services.
- Young people in the UK also report perceived **barriers in their access of health care** [46,47] with similar reports from Australia [48] and the USA [49]. Fifty per cent of young people report having visited the GP in the last 3 months with 85% doing so within the last year [50]. However, of these, over a quarter of the girls, reported feeling uneasy or very uneasy doing so [50]. Young people with a range of chronic illnesses also report various practical, behavioural and attitudinal barriers to their communication with doctors including perceived attitudes towards adolescents, communication skills of the adolescent and health professional; the type of information needed; a perceived lack of interest in wider impact of chronic illness; presence of parents and students/trainees; duration and frequency of contact and gender of the doctor [51].
- Several authors have reported that **transfer can also be of less concern and/or uneventful** for at least a significant proportion of young people [52-54]. The interpretation of such studies must always be carefully considered in context. In a US-based study, Telfair et al reported that adolescents with sickle cell disease had mixed emotions/feelings regarding the transfer process with 67% indicating that they would be “okay” with the transfer to adult [54] but obviously had not yet experienced it to be objective about it. A more recent national study by the same authors reported a third of adolescents having no concerns about transfer [55]. One reason for young people not perceiving a need for a transfer intervention program is that they felt they received enough help already [54]. Young people who had the same rheumatology team from diagnosis through into adulthood expressed fewer concerns about transfer [36]. However, many young people felt that professionals who had known them as children failed to see them as the young adults they now were and respond to their changing needs [36]. These participants also found it more difficult to be seen independently as there was no natural break in the status quo. In the study reported by Bussing et al 75% of the young people had what was ill defined as “allergic conditions” [52]. Eiser et al reported results from a diabetes clinic for under 25 year olds that “transition can be generally achieved non-traumatically” but the mean non-attendance in the study was 18.9% (range 0 to 80%)! [53].

3.3 Increasing numbers

10-20% of adolescents have a significant on-going health care need related to a chronic health condition [15, 56, 57]. With rapidly evolving medical technology and improvements in therapies and medical care, there are increasing numbers of young people with chronic illnesses and/or disabilities surviving into adulthood where previously they died in childhood e.g. cystic fibrosis; inherited metabolic disease, congenital heart disease, cancer and transplantation, haemoglobinopathies, cerebral palsy etc.

- One per cent of all newborn babies have **congenital heart disease**. Forty years ago, 70% of such children would have died before the age of 10 years. In 2005, 85% will survive into adulthood [58]
- Since its first recognition as a disease entity in the 1930s **cystic fibrosis** has improved from a 70% one year mortality rate such that the median survival is predicted to be 40 years for a child born in the 1990s [59,60].
- Around 70% of young people with **cerebral palsy** will survive into adulthood [61], more than 50% of children with **spina bifida** [62] and 53% to 25 years for boys with **muscular dystrophy** [63].

There is evidence of **increasing incidence and/or prevalence and/or recognition of diseases** specific to the adolescent age group e.g.:

- During the past 25 years there has been an increase in the incidence of **cancer** in the adolescent and young adult age group but this has been associated with a lower reduction in mortality compared to younger and/or older patients [64].
- There is an increasing prevalence in **diabetes** during adolescence [65]

There is evidence of **increasing morbidity of childhood-onset disease in early adulthood** e.g.

- Late asymptomatic shunt failure in adults with **spina bifida, hydrocephalus and shunts** occurs primarily in early adolescence (13%) then 4% per year thereafter, with associated chronic morbidity and/or death [66]
- Half of childhood **cancer** survivors will have or will develop disabilities severe enough to affect quality of life. [67]
- 35 % patients with a **renal transplant** transferred to adult nephrologists, 35% had lost their graft within 36 months of transfer [68].
- Pain reports in childhood and early adolescence have been reported to be associated with the report of pain in early adulthood [69]. A cost-of-illness to UK society of **adolescent chronic pain** has been estimated at approximately £3840 million in one year [70].
- In the **Diabetes** UK cohort the death rate per 100 000 person years was increased 12 and 14 fold in males and females respectively aged 20 and 29 years [71].
- **Mental health problems and disorders** from childhood and adolescents have been found to predict later social difficulties [72,73] and long-term health and social care costs [74].

There is **increasing recognition of the importance of recurrent disease and/or new young adult morbidities** of childhood onset disease

- **Recurrent disease** e.g. over a third of young adults with **juvenile idiopathic arthritis** (JIA) will have ongoing active joint inflammation [75,76] with significant burden and cost of illness [77].
- There is increasing recognition of conditions during childhood which are as yet unmatched by dedicated adult services e.g. **autistic spectrum disorder** [78], **attention deficit hyperactivity disorder** [79].
- Increased cardiovascular risk factors in adult survivors of **childhood leukaemia and malignancies** [80,81].
- The mortality rate for 5-year survivors of childhood cancer is greater than tenfold that of the normal age adjusted population [82].
- Increased risk of second malignancies in adult survivors of **childhood cancer** [83].

- **Osteoporosis** is increasingly recognised in association with many chronic childhood-onset diseases [84]. For example, in a population-based study of adults with **JIA** (of which the majority had arthritis limited to less than 5 joints), 41% were osteopaenic [85]. Three of the 4 relationships of the low bone mineral density included adolescent determinants i.e. calcium intake, lack of participation in organised sports and smoking during adolescence [85].
- A lack of intimate relationships and relationship difficulties (males) have been reported in studies of young adults with **JIA** [86-88], with 58.3% reporting disease related sexual problems [88].
- A recent study has highlighted the importance of **vocational morbidity of disability** [89]. Burchardt reported that although there is no difference in the scope and/or level of aspirations among **disabled 16 year olds** and their non-disabled counterparts in the UK, there is a significant divergence of experience and aspiration in early adulthood [89]. This echoes the results of other earlier UK studies [76, 90, 91]. Compared with sibling controls, survivors of **leukaemia, non Hodgkins lymphoma and neuroblastoma** were significantly less likely to graduate from high school and had increased use of special education services [92]. Hunt et al reported a concerning link between shunt revision in young people with **spina bifida and hydrocephalus** and achievement in adulthood [93]. Unemployment however is not always found to be related to educational achievement or disability [75,76,90] and raises the possible contribution of other factors of vocational readiness [94]. Lower expectations of teachers, career advisors, and potential employers have recently been reported by young people with **JIA** [95]. Data regarding vocational outcome and morbidities are important, least of all because the per capita public finance lifetime costs of not being in education, training or employment has been estimated to be £52 000 for 16-18 year olds [96]. Three of the five key objectives of the “Every Child Matters” cross-government programme are therefore particularly welcome i.e. enjoying and achieving; making a positive contribution and achieving economic well-being [12].

3.4 Loss to and lack of follow-up post transfer

Loss to and/or lack of follow-up following transfer to adult services have been reported in several conditions e.g.

- 10-69% of young adults with **diabetes** have no medical follow-up after leaving paediatric care [53, 97,98] and are potentially subject to higher rates of disease-related complications. In a UK study of a cohort of patients 2 years post transfer, 51% of transferred patients were still attending compared to 92% 2 years prior to transfer (p<0.0005) [99].
- Tomlinson et al reported 100% follow-up until age 16 years of young people with **spina bifida complicated by hydrocephalus** but only 40% in young adulthood with the associated concern re late shunt failure discussed earlier [66].
- Earlier studies have reported that after leaving school, young people with **physical disabilities** had significantly less contact with health services and reported untreated health problems [100, 101].

3.5 Current limited service provision

There is evidence of need for service development as in the rest of adolescent health in the UK [23, 102]. Studies have reported no adolescent or transition clinic provision in 82% of **rheumatology clinics** [103], 47% of **paediatric diabetes centres** [104] and two thirds of **paediatric gastroenterology services** [105]. Furthermore there is limited provision of dedicated **adolescent inpatient units** to support such services [23,24]. Unmet **mental health** service needs for young people aged 16-19 years have also been reported by professionals from mental health, social, education and non-statutory services [106].

The evidence of limited service provision is particularly pertinent to adolescent onset disease, which only presents during adolescence and may be diagnosed within paediatrics and yet local policies may determine transfer shortly after diagnosis. Over a quarter of **JIA** starts during adolescence [107]. Two thirds of young people with the classical adolescent condition of **chronic fatigue syndrome** have significant symptoms persisting 13 years after diagnosis [108], highlighting the need for transitional care for such individuals. Similar issues face young people with **life-limiting conditions** [109].

Difficulties in identifying young people with unmet needs due to **inadequate information systems** have also been reported [40]. Young people with physical disabilities and/or chronic illness without a significant learning difficulty may not have an education statement of special needs and therefore will not be on any centralised list. In a national, multicentre study, the minority of adolescents with **JIA** had a statement and yet reported unmet vocational needs [107].

Several studies have highlighted the **differences in service provision** between paediatric and adult services [36, 110]. A reduction in services e.g. therapy has been reported by several authors [36, 110] despite the fact that most young people with disability have ongoing health problems [110]. Young people themselves have also reported their own difficulties in appreciating why they were no longer be entitled to services previously offered by the paediatric team (e.g. hydrotherapy), despite remaining with the same consultant and within the same hospital [36]. The lack of information made available to young people and their parents about future options and opportunities and the sorts of services and support that will become available on transfer have also been reported [36; 111-113].

3.6 The differences between paediatric and adult health care

Paediatric and adult health care are two “very dissimilar systems and cultures of care which serve distinctively different populations with divergent health care needs” [114] and therein lies the challenge of transition! Examples of some of many and varied differences between paediatric and adult health services are listed in table 4.

Table4

Differences between paediatric and adult health services

- Age range (!)
- Cultures of care
- Recognition of growth and development
- Consultation dynamics
- Communication skills
- Generic issues
- Role of parents
- Role of family
- Role of peers
- Educational issues
- Vocational issues
- Confidentiality issues
- Tolerance of immaturity
- Procedural Pain Management
- Spectrum of diseases
- Impact of disease
- Legislation
- Service provision

These differences are perceived by the young people themselves. Young adults with **diabetes** viewed paediatricians as emphasising family, social life, school and work in contrast to adult physicians who were more pre-occupied with the risk of long-term complications, importance of exercise and stricter glycaemic control [53]. The **different cultures of care** between paediatric and adult services [115] need to be acknowledged by both health care providers as well as in transition programmes in order to prepare the young person and their caregivers for these differences.

3.7 Potential delayed adolescent development into young adulthood

One of the essential attributes of health professionals involved in the care of adolescents is a working knowledge of the reciprocal influences of adolescent development on the health of the individual young person [116]. **Development should be used as a lens to look at adolescent health** in its entirety, acknowledging the interrelationships of physical, cognitive and psychosocial development. The potential for delayed development needs to be recognised when considering those with chronic illness and/or disability. For example, Britto et al reported that the age of onset of risky behaviours in young people with cystic fibrosis and sickle cell disease were frequently older than a control population [117]. During policy and service development, the need for age and developmentally appropriate care within adult services is therefore important particularly when considering delayed development.

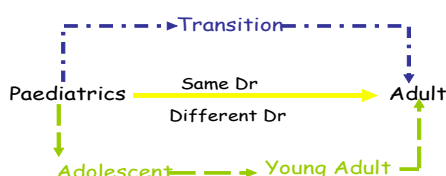
4. EVIDENCE OF PROCESS

In addition to evidence of need, research has also provided clues as to the sorts of support and service configurations that need to be in place to ensure positive transitions.

4.1 Transition Models

There are various models of transitional care provision in practice in the UK currently as exemplified by Figure 1.

Figure 1
Models of Transition in the UK



Sawyer and colleagues describe 3 general models for transition - disease-focused, primary care and generic adolescent health services [118]. While et al developed this further and described 4 models, proposing that future research should be based on such models (see table 5) [6].

Table 5
Models of Transition for Evaluation proposed by While et al [6]

1. Direct transition (communication and information sharing only)
2. Sequential transition (includes the development of new services)
3. Developmental transition (includes skill training and support system development)
4. Professional transition (transfer of expertise only)

A survey of 126 interdisciplinary transition programmes in the US revealed the majority to be condition specific (62%) with the rest being generic to adolescence and transition [119]. Very few were primary care based and the majority were problem focused rather than being health promoting [119].

4.1.1 Young Adult Clinic Models

One major UK based study reported that a **young adult team approach** for young people with disabilities cost no more to implement than an ad hoc approach and was more likely to enhance participation of involved young people in society [120]. Orr et al reported no negative impact on glycaemic control of transfer from a paediatric to a **young adult programme** for young people with diabetes (17- 25 years) involving paediatric and adult providers [121]. The evidence of the **prevalence of adolescent onset disease**, the **disproportionate disadvantage of the 16-25 year old age group** [14] and the **significant morbidities specifically associated with late adolescence**, provides further support for the development of young adult clinics as espoused in the care of young adults with diabetes [18, 53]. Richards and Vostanis reported that mental health professionals strongly stated that the 16-19 year old age range must be accorded a separate identity with greater consideration of their need [106]. Within many services like diabetes and rheumatology, there will be people diagnosed in late adolescence and young adulthood who have never experienced paediatric care, further highlighting the importance of ensuring the provision of age and developmentally appropriate care beyond the event of transfer in adult services [18].

Tucker and Cabral have recently described a model of a "young adults with rheumatic disease" (YARD) clinic for young people aged 18-24 years [122]. The **young adult clinic concept** is particularly appropriate to address the discrepancy between average age and/or case mix of patients between paediatric and adult clinics e.g. diabetes, arthritis. Furthermore they potentially facilitate uninterrupted health care provision of age and developmentally appropriate care and the completion of the other key adolescent transitions in terms of vocation, independent living etc. Finally, young adult clinic development will facilitate the development of transitional care and adolescent health care provision within the adult facility and potential paediatric-adult collaboration in terms of clinical service, education and training and research.

4.1.2 Primary Care Models

The GP is an obvious candidate for a key worker role as he/she can potentially provide continuity of care for such young people. However it is unclear as to how this role is perceived and put into practice by GPs currently. The majority of transitional care models known to the author are not primary care focussed either in the UK or the USA [119]. In the Children's NSF however, the role of primary care in transition is listed as an important component of transition policies "for continuity and to meet broader health and social care needs" [10,11].

A Canadian study of young adults with **diabetes** reported that the family physician was the 3rd most requested health care professional they wanted as a member of the diabetes care team after the endocrinologist and the dietician [42]! In contrast, in a national survey of professionals involved with adolescents with **JIA**, less than half perceived the GP to be important in the planning of transitional care [37]. In their US-based study, Telfair et al reported that 81% of family practitioners reported no involvement in transitional care for adolescents with **sickle cell disease** [9].

Addressing "broader health needs" is an obvious potential role for GPs and was certainly called for by young people with JIA including sexual health issues [36] echoing studies in other chronic illnesses [e.g. 123-125]. Chronically ill adolescents have been reported to be as likely or more likely to take risky behaviours than their healthy counterparts and should receive the same anticipatory guidance [126], which may not always be available in specialty

services [127]. GP's are also the most likely to provide the patient with the **only medical continuity during the period of transfer** and are important in encouraging skills for appropriate health care utilisation. Learning to access health services independently has been shown to predict successful transfer [5]. In a trial of transitional care involving over 300 adolescents with **JIA**, the proportion of adolescents seeing the rheumatologist independently was significantly higher than the proportion seeing their general practitioner (GP) alone [107]. Primary care teams may be particularly important for those **patients who choose not to addend specialist adult services** by allowing some opportunity for monitoring and addressing physical health and psychosocial well-being. In a US study, physician time constraints were reported to limit their potential involvement [128]. GPs may be unsure of their role with young people with disability and/or chronic illness, tending to leave issues to hospital consultants [110]. When there is no adult equivalent of "community paediatrician", young people with disability may be discharged to the care of the GPs by their community paediatricians even when the former have had variable involvement in the care partnership prior to discharge [40].

4.1.3 Transition Personnel

Although there is no robust evidence to support one type of model over another (except for the Leeds study comparing the young adult team versus ad hoc services [120]), there is valuable evidence to support certain individual components of transition within these models e.g.

- In several studies of different chronic diseases, young people have reported a preference **in meeting adult doctors prior to transfer** [36, 42, 43,99, 129 -133]. In diabetes clinics there was a higher rate of adherence to appointments in units where the young people had met the adult doctors prior to transfer [99]. Interestingly, providers treating both adolescent and adult populations have been reported to be more likely to demonstrate transition in practice compared to other professionals [9].
- **The role of a key worker and "case management"** has been advocated by many authors [61, 114, 134-137, 138]. In a study of young people with cerebral palsy, Stevenson et al reported poor communication both between agencies and families as well as inter-agency and supported the identification of a "care coordinator"[61]. The role of such professionals is potentially diverse and wide-ranging – including clinical expert, consultant, change agent leader, researcher and educator to name but a few [114]. In a multicentre study of transitional care in rheumatology, the local coordinator role was considered better than paper based resources by the adolescents themselves [136]. In the latter study, the role was undertaken by a range of personnel including occupational therapists, nurses and physiotherapists [136]. Nurses are the profession most frequently advocated for this role in the literature [28, 114]. Telfair reported that nurse practitioners were more likely than other providers to demonstrate transition in their practice [9]. However, with the raised awareness of transition and increased opportunities for training, the potential for other professions should not be underestimated and instead, be recognised, encouraged and obviously, evaluated!

4.2 Transition Programmes

The essential components of transition have been reported by many authors [1,2, 8,9, 10,11,29,30,35,54,55,139,140] but not always supported by an evidence base other than user and/or provider accounts.. Current literature of service evaluations also is confusing with respect to what is meant by the term transition and whether it refers to simply the configuration of services and/or the content of the service provided i.e. a transition programme of care. The development of systematic transition programmes has been supported by the majority of professionals in several major surveys [9, 37]. Although there have been reported evaluations of "transitional programmes", the specific details of the individual components of such programmes procedural factors and logistics are not often

detailed. Furthermore, a weakness of the current evidence base is that, despite evidence which shows how the different aspects of adult status are interdependent [e.g. 113,141], research projects have tended to focus on a single aspect of transition e.g. leaving home, transfer from paediatric to adult clinics, as opposed to taking a truly holistic view of transition. The author has recently reported the specific details and evaluation of a transitional care programme in rheumatology based on evidence from an extensive needs assessment [136]. A table summarising the evidence on which the programme was based on is included in the paper [136].

Some authors have only reported on the medical components of transition and not addressed the vocational or psychosocial components [142]. Several studies have shown that transition services do not pay attention to the things that are most important to young people such as friendships, social life and leisure [36, 45, 111]. Young people themselves perceive lack of awareness of this wider impact of their condition by health professionals [36, 51, 143].

4.3 Planning

In a 10 year audit of admissions of young adults aged 18 years and over to a major Australian paediatric hospital, 51% of surgical inpatients and 28% of medical inpatients had no documented plan for transition to adult care [144]. In addition to lack of planning, **disease complexity** was reported to have contributed to the increased admissions [144]. Fiorentino also reported complexity as a negative predictor for transfer of young people with physical disabilities [110]. The American Academy of Pediatrics have recently described the criteria for adequate provision of a primary care medical home for children and youth with cerebral palsy which included, written care plans with regular review and an emergency care plan in addition to early responses to family support needs to enhance resilience and coping [145]. In a national survey of professionals involved in the care of adolescent with JIA, 77% of health professionals felt that individualised transition plans were *important/very important* for adolescents with JIA [37].

Research has consistently shown that many young disabled people and to a lesser extent their parents, are not properly **involved in decision-making** within the transition process [111, 146,147]. In various studies, young people have been very clear as to their desire to be involved in planning and/or goal-setting with their health care team [42, 148]. In their survey of over 250 families, Heslop reported that 4 out of 10 young people had little if any involvement in the transition planning process with a quarter having no involvement [111]. Dee and Byers have highlighted the ways in which young people with out speech are particularly vulnerable to being excluded from the transition planning process [149]. In transitional care as with the rest of adolescent health care, it is important that health professionals engage the young people themselves when providing such care [150]. When **individualised transition plans**, developed with the young people and with their parents respectively, were implemented in a programme of transitional care, they were successfully completed by 95% and 92% of adolescents and their parents respectively, successfully identifying their needs [136]. Various other templates have been reported albeit not formally evaluated [e.g. 29].

4.4 Timing

Many authors have discussed the need for consideration of the many determinants of the timing of transition and transfer in development of transition policies [e.g. 1,2,8, 139, 140, 151] but again with a limited evidence base other than qualitative data from user accounts.

Preliminary data from UK studies support an **early start to transition** with maximum improvement in disease knowledge in early adolescence with 11 and 14 year olds reporting scores after 12 months participation in a transitional care programme significantly greater than those of 17 year olds at baseline [152]. This fits naturally with the concurrent transfer to

secondary school in the UK. According to the Statement of Special Educational Needs (SSEN), a transition plan should be in place for such young people by the age of 14 years [153]. However, a significant proportion of young people with various chronic illnesses do not have an SSEN [e.g. 36]. The negative predictors for transfer in young people with disabilities reported by Fiorentino included the lack of statement of special educational needs [110].

There are **different perspectives as to when is the right time** to start components of transitional care within the doctor-family relationship. Health care providers have been reported to consider a significantly earlier age for young people to start being seen independent of their parents and to start teaching them self-management skills [134].

Finally, there are particular issues regarding timing of transition and transfer for young people who only present during mid adolescence and for this with life-limiting illness. The ideal service for such young people is a dedicated young adult service that bridges the gap as discussed previously [109].

4.5 Skills training for young people during transition

The concept of young people being **the “new users” of health services**, the latter having been accessed previously by their parents/caregivers on their behalf, is useful when considering the skills training component of transition (table 2). Young people ideally need to become the **“independent managers of their health care personal mastery”!!** [154]. This has been reported to be associated with positive medical outcomes e.g. diabetes self-management education and coping skills training programmes have been shown to improve metabolic control, self-efficacy, and quality of life in adolescents [128, 155, 156-157].

Skills training in self-advocacy for young people with chronic illness and/or disability reflects the resilience framework integral to transitional care and adolescent health [158]. Examples of self-advocacy in healthcare includes feeling confident to see the health professional independent of their parents when the young person so chooses, accessing healthcare independently, awareness of own health, own knowledge of medical condition and/or therapy, self-management of their condition, etc

One key opportunity for the development of self-advocacy within the healthcare setting is **feeling confident to choose to see the health professional alone**. This was reported to be one of the 5 main methods of “demonstrating transition” by providers of health care for adolescents with sickle cell disease in the USA [9] along with encouraging patients to accept more responsibility, providing literature, making the patient more financially responsible and having family conferences to discuss transition [9]. Independent visits have been shown to be important as one determinant of attendance at 1 adult GUCH clinic appointment [5] and as an associated factor with improvement in health related quality of life in adolescents with JIA [152]. In a Delphi study involving adolescents with JIA, parents of adolescents with JIA and a range of health professionals involved in their care, one of 6 features of what was considered best practice and feasible in the majority of UK hospitals was giving adolescents the option of being seen by professionals without their parents [39]. However, although young people report valuing such opportunities [36, 44], not all services facilitate them [107, 159, 160]. Young people may also be unaware of their rights to choose to be seen independently and it is therefore important to proactively inform them with inclusion of such information within clinic literature and advertising with posters in the waiting room etc. In any discussion of such “independent” visits, consideration must be made as to the informed choice of the young person, their right to a chaperone of their choice (and not assuming that this will always be a parent) and the skills in terms of confidence and communication required on the part of the young person themselves to participate effectively in such dyadic consultations [51].

Salient information, that is age and developmentally appropriate, is an integral part of self-management and informed consent for young people with chronic illnesses. Such information is requested by both young people and their parents but is not always available or perceived as satisfactory by them [18, 36, 37, 161]. **Education** was one of the most recommended services that young adults reported as an essential for an ideal diabetes centre. The top 3 topics were “what’s new in diabetes research”, stress management and sexual health [42]. The range of information needs requested by young people is potentially wide and often extends beyond the medical aspects of the condition [18, 36, 42]. Similarly, information about drug therapy requested by young people includes rationale and risk-benefit discussions and not just details of daily regimens and side effects [36]. Having a full understanding of their illness and being involved in medical decisions was rated as important by over two thirds (69%) of young adult survivors of a paediatric dialysis and transplantation programme and as the most helpful coping strategy overall by 36% [91]. Effective information has also been reported to improve quality of life [162], adherence with health regimes [162] and coping with chronic disease [163-165].

Knowledge deficits in both adolescent and adult populations of childhood-onset disease have been reported by several authors including knowledge about basic aspects of diagnosis and treatment [166, 167, 168]. Knowledge is important for various reasons eg for disclosure to potential partners or employers, an unmet transitional need reported by adolescents themselves [36, 54].

Understanding the implications of the condition and its therapy on other aspects of health is equally important. For example, understanding the implications of a chronic illness and/or disability to sexual and reproductive health was considered a key aspect of transitional care by doctors and yet the area of greatest gap between perceived importance and effectiveness [169]. Sexual health is important for many reasons least of all the development of a sexual identity as well as consideration of physical limitations, heredity, pubertal effects, teratogenicity etc. The reported lack of discussion addressing sexual health issues [123-125, 170] is supported by the lack of documentation in case-notes of adolescents with chronic illnesses [159]. Such data is worrying in that young people with chronic illnesses and/or physical disabilities are reported as at least sexually active as their peers [126, 171, 172]. However their levels of contraceptive knowledge/use tends to be lower than their able-bodied peers [171] and they experience more negative consequences of their sexual behaviour in terms of sexually transmitted infections and abuse [172]. There is some evidence that adolescents who have “beaten” a life threatening illness such as cancer are actually greater risk takers [173]. The maturational challenges of having a chronic illness during adolescence may also lead to young people engaging in risky behaviours as a means of achieving developmental goals such as peer acceptance and independence.

Promoting self-management in young people with chronic illness can be difficult for parents and health care providers [174]. Discrepancies in the “right age” for self-management practices between parents and health care providers have been reported (see above) [134]. Similar discrepancies have been reported in the perceived importance of discussion of sexual health and substance use issues with young people with special health care needs with health care professionals perceiving significantly greater importance [134]. The absence of a parent has been reported to be related to effective discussion of sexual health issues within a clinic setting although such discussion was rarely initiated by the young person and was also related to the positive attitudes and comfort level of the health professional [175]. In several studies, young people have expressed their wish for professionals to be honest and not to hold back or be gatekeepers of informational resources [36, 143, 176]. Professionals need to be aware of the potentially competing aspects of the parenting role during transition i.e. protecting their son/daughter’s health while supporting their growing need for independence, privacy and autonomy. Optimal care may or may not be achievable, depending on a young person’s level

of development and often negotiation of compromises between parent and young person are required – always with regular review!

4.6 Transition for parents

Research specifically addressing parental aspects of transition is limited other than evidence of need [e.g. 36, 54]. The Children's NSF advocates the need for "services to seek to support parents in particular providing information and advice on how they can appropriately support their child's transition to adulthood [10,11]. **Family connectedness** ("to enjoy, feel close to and cared for by family members) in addition to school connectedness (to enjoy school and experience a sense of belonging) has been reported to be protective against a range of adolescent risk behaviours (except a history of pregnancy) [177]. Factors associated with **resilience for young people** with chronic illness and/or disability have been reported to include family support and parent support without over protectiveness in addition to self-perception as not being handicapped, involvement with household chores, having a network of friends which are both disabled and non-disabled, and peer support [178].

There is evidence of the negative impact of parenting behaviour during transition. A third of health professionals reported parental difficulties during transition and perceived parental and family factors as influences of successful transition [37]. **Getting the balance right** is challenging for parents of any teenager, let alone those with the added challenge of chronic illness and/or disability. Parental overprotection has been reported as a key challenge by adolescents with cystic fibrosis post lung transplant [148] and as a reason for unemployment by young adult survivors on the renal transplant registry [179]. A third of young people with cerebral palsy [12-22 years] felt their parents were overprotective and a quarter actually objected to this. [123]. When compared to the rest, these young people had less happiness, self-esteem, less perceived popularity, more self-consciousness and higher anxiety [123]. Conversely, several authors have reported young people citing their parents as the reason behind them getting a job or living independently rather than the service providers [112, 141, 180].

In the clinical setting it remains imperative to acknowledge and actively believe in **both the adolescent and parental perspectives**, particularly as discordance may be associated with depressive symptoms [181]. However, where adolescents are unable or unwilling to provide self-reports and a parent proxy is used, careful consideration must be given to how reliable they may be. Several authors have reported significant discrepancies in adolescents and their parents in various settings [182 – 185]. In a study considering both adolescent and parent-proxy ratings, 50% of parents of adolescents with JIA (n=303) either over estimated or underestimated their child's pain, functional ability, global well-being and/or health related quality of life [182]. Parents and children tend to agree about easily observable behaviours compared with less overt phenomena [e.g. 182]. Family dynamics change considerably in adolescence, with young people becoming increasingly emotionally autonomous from parents and wanting to spend more time away from home. Further research is needed to understand what other factors may influence the quality of parent-proxy report, especially as these same factors are also likely to affect the clinicians ability to accurately understand their patients' outcomes. This may be especially important in adolescence, which is characterised by less stable and more maladaptive coping patterns [184, 185] than adults.

The challenge to health care providers is advocating for the young person while remaining **inclusive of the parents**. In the context of life threatening illnesses it is particularly important for health professionals to be aware of the executive role of the parents and avoid any marginalisation of young people in the development of therapeutic alliances [186]. Parents have suggested ways for health professionals to help them to become better advocates for their children [36]. These include professionals actively involving young people during consultations, continuity in professionals to build trust [36]. With these in place, parents perceived they would be able to gradually withdraw from their primary role in triadic

consultations [36]. However, they also proposed that this would provide time for their own needs to be met [36] with respect to parenting an adolescent with a chronic illness and/or disability as advocated in the children's NSF [10,11]. In a US-based study of adolescents with sickle cell disease, Telfair et al reported that 44% adolescents reported that transition programs should offer "ways to help parents let their adolescents grow up"! [54]. Such service provision has obvious resource allocation in terms of clinic space and/or time in addition to staffing levels, particularly for those practitioners not working within a multidisciplinary team.

4.7 Multidisciplinary and multiagency approach

Due to the holistic nature of transition, care will by definition require a **multidisciplinary and multiagency approach**. The heterogeneity of these "virtual teams" has major implications to effective communication within and between services. Poor intra-agency and inter-agency coordination were reported by rheumatology professionals in a national survey of transitional care needs for young people with JIA [37]. **Cross-boundary working** has intrinsic challenges itself never mind in a relatively new area such as transitional care. These challenges extend into the realms of joint commissioning for transition between disciplines in addition to between paediatric and adult sectors, as well as to research where multiple agencies and disciplines with all the inherent variation presents major methodological considerations.

4.8 Information transfer

The multidisciplinary and inter-agency aspects of transition present significant challenges to information systems and processes. **Documentation of relevant information** is important in view of both the multidimensional and multidisciplinary nature of transitional care. Unfortunately in a national audit of case-notes of recently transferred young people to adult rheumatology care there was limited documentation of key transitional care issues in the case notes although this significantly improved following centre participation in a transitional care research project! [159]. Similar problems with **information exchange** between paediatric and adult specialists were identified in a French study of the transfer arrangements of adolescents with diabetes [187]. At this stage of service development, the educational value of case notes and letters should not be underestimated to raise awareness throughout the health service.

Effective communication across disciplines and services and between paediatrics and adult services is imperative and yet challenging in view of the number of professionals involved in addition to the need for it to remain inclusive of young person and family. The message of seeing a thin set of notes on arrival to their first clinic visit in the adult service can be disheartening for the young person who may have had several weighty volumes in the paediatric service, particularly if they had onset of disease in early childhood. Young people and their parents have expressed specific fears regarding the actual transfer of information [36, 188]. Sawyer et al also reported that the summary of such medical records in anticipation of transfer can take paediatric providers up to 4 hours per record on average [188]. Despite participation in a multicentre transitional care research programme, there was unfortunately no improvement in the number of patients for whom copy letters and/or medical and/or multidisciplinary team summaries were sent to the adult team prior to transfer [159].

The **importance of adequate administrative support** has been acknowledged in the NSF [10,11] and is likely to be a determinant of successful transfer ultimately. The actual resource allocation for such support however is less clear. The NSF also advocates the development of patient held records particularly for those young people with complex needs [10,11]. The practice of sending copy clinic letters to families is likely to assist in this regard [189] although the implications of sending copy letters direct to the young people has not to date been specifically addressed particularly with respect to confidentiality, comprehension, adolescent satisfaction etc. [190].

4.9 Importance of Place and Environment

A national survey reported the need for 12.8 inpatient beds for every 10 000 adolescents aged 12-19 years in the hospital catchment area and called for the provision of **dedicated facilities for adolescents in hospitals** [24]. Kari et al reported 30% of teenagers surveyed had been admitted to hospital with 53% admitted to a paediatric ward and 81% to an adult ward with the majority feeling “out of place” irrespective of the ward [191]. Several studies have echoed the NSF findings with young people reporting that they dislike paediatric environments, which they find patronising, that they find adult environments distressing and both environments, isolating [10,11,36]. Young people call to be valued and to feel normal with age appropriate, dedicated adolescent areas [e.g. 36]. Other authors have reported overall satisfaction with healthcare irrespective of whether it is a dedicated adolescent unit or a split site unit between paediatric and adult care [192]. However, in the latter study there were still significant differences noted in recreational and relaxation facilities, studying space, ward noise and company of the same age [192]. Dedicated adolescent environments was one of 3 components of transitional care considered by a panel of users and providers in a Delphi study to be best practice but feasible in only a few UK centres [39]. A recent policy document has summarised the key attributes of young person friendly health services and will provide an important benchmark to build future services upon [25].

4.10 Involvement of YP in development of services and policy

Recognition of the **rights of young people to be heard** is enshrined in the 1989 UN convention of the Rights of the child, ratified by the UK government in 1991, in which Article 12 confirms the fundamental right of the child to express his or her views in all matters affecting the child. Research has identified differences between the views of young people and the view of the adults close to them, suggesting that adults cannot be used as reliable proxies for children and young people’s views [e.g. 181-183, 193]. There have been many recent initiatives, including from the Department of Health, to involve young people’s views in matters that concern them [10,11, 194,195]. The RCPCH has recently published their well-considered **strategy to promote participation of young people** in college activity [196]. Actively involving young people in decision-making promotes citizenship and social inclusion, important for the health of the community. Moreover, strategies for enhancing participation will develop self-esteem, personal development and a range of skills in young people. In a postal survey of 99 health authorities and 410 NHS Trusts, a third had someone with designated responsibility for children and young person’s involvement. Of 27 initiatives identified, only 17 had resulted in change and only 11 had involved YP in consultation AND decision making [197].

5. EVIDENCE OF BARRIERS

Although the philosophy of transition has been accepted both nationally and internationally for over a decade, **the challenges of translating policy into practice** remain. Legislation, policies and policy guidance do not guarantee change or improvements. Despite the consensus statement published several years previously, a US-based study of 4332 young people with special health care needs, half had not discussed transition and of those who had, only 59% had a plan and only 42% had discussed transfer to adult care [198]. In a multicentre transitional care research project in the UK, only 2 of 10 participating centres had a written transition policy at the start and although an easy-to-use template was provided in the study resources, no additional centres had developed a policy at the end of the 3-year study [136]. In a major UK paediatric hospital, a similar template was developed by a multidisciplinary group of representative professionals but only 5 of 38 specialties had developed a specialty specific policy 2 years following implementation [199].

Education is no different. Despite a clear legislative and regulatory framework [153], young people with learning difficulties are still leaving school without any recognisable form of planning [147]. In a study of young people with physical disability, Fiorentino et al reported

that a lack of an educational statement of special educational need was a negative predictor of successful transition [110].

The barriers to provider involvement in transition have been discussed by several authors (see table 6) and are largely similar irrespective of country of origin [37-39, 134, 136, 169, 200-204]. Some of the main barriers are discussed further below.

Table 6
Potential barriers to successful transition

Time
Training of professionals involved
Financial e.g. insurance, resources for service provision
Different perceptions of young person, parents, providers
Attitudinal
Discomfort of professionals involved
Lack of applicability
Difficulty accessing resources
Poor intra-agency coordination
Poor interagency coordination
Difficulties addressing parental issues
Adolescent resistance
Family resistance
Lack of institutional support
Lack of planning
Lack of appropriate adult specialists

5.1 Time

Time has been reported to be a major barrier to provider involvement in transition by several authors [38, 134, 136]. **Adolescent clinic appointment times** have been advocated to be longer than both paediatric and adult clinic appointments due to the complexity of adolescent health service delivery [30]. Certainly paediatric appointments tend to be significantly longer than adult clinic appointments in a UK setting [205], although sometimes adolescent consultations are perceived to take longer than other age groups when this is not true in practice [206].

5.2 Training

In a US-based survey of physicians, there was a significant gap between their perceived importance of transitional care and their perceived effectiveness in the latter [119]. Telfair et al reported that although the majority of providers agreed that a transition program was necessary for adolescents with sickle cell disease, few actually did anything to demonstrate their involvement in the transition process [9]. Such findings echoed by other surveys [37,38] support the need for increased guidance, education and training both at practice and policy level. The current background of **limited training opportunities in adolescent health training** for both paediatric and adult care providers will impact on delivery of transitional care in UK. The lack of training has been reported as a major barrier by several authors [37,38, 134] with 43% of health professionals in a national survey of transitional care on rheumatology reporting unmet training needs [37]. Health care providers have reported perceived discomfort with transitional care issues, ambivalence about their role and perceived lack of applicability as potential barriers to delivering adolescent health care. [160, 207]. **Professionals knowledgeable in transitional care** were considered best practice but only feasible in a few hospitals in a UK Delphi study [39]. The latter study echoed other studies, which identified a lack of specialist staff available to work with young people and their families around the time of transition and/or specialist transition services unable to meet the

demand [111, 146]. UK data with respect to training needs in transitional care must be considered in the context of the lack of formal training opportunities in adolescent health in general unlike the situation in Australia and North America. In a survey of staff in a major UK paediatric hospital, 60% of respondents reported that they had received no prior specific training in adolescents health with no significant difference in these needs observed between doctors and other health professionals (AHPS and nurses) [208].

Training needs in one component of transition i.e. vocational readiness have received welcome attention in the literature recently [95, 209]. In view of the vocational morbidity reported in young adults with chronic illness and/or disability [75,76, 89, 90, 179], the ability of health professionals to address such needs if only to signpost, is an important transitional care skill. However, the evidence suggests unmet needs within this area [95, 208-210]. Limited provision of careers counselling in transition programs has been reported [103] despite evidence that young people themselves want such support [36, 95, 210]. A lack of awareness of such aspects by health care professionals may also be at play. A national survey of occupational therapists by the author has reported that although OTs felt it was important and appropriate for OTs to address the vocational issues of adolescents with a chronic illness, they reported limited perceived knowledge and confidence and significant unmet training needs [211].

Lack of training in transitional care is not limited to health professionals. Grove and Giraud-Saunders identified difficulties with respect to providing the Connexions service to young people with learning difficulties because of both the lack of special skills and expertise in learning disability held by Connexions Personal Advisors (PAs) and an insufficiency in the number of PAs available [212].

There is now evidence that **training in adolescent health is beneficial!** Sustainable, large improvements in knowledge, skill and self-perceived competency were reported in a randomised control trial within primary care in Australia, which were sustained at 1 and at 5 years [213,214]. Furthermore, other authors have reported positive outcomes of such training including higher rates of desired clinical practices e.g. confidentiality, screening [213; 215-217], greater number of adolescents seen [218] and a greater tendency to engage in continuing education in adolescent health [213,214, 218]. The potential of using transitional care as an invaluable model to teach patient and family centred care, differences between paediatric and adult care, dyadic vs. triadic consultations, cultural competencies and shared decision-making should not be underestimated [219].

5.3 Money

Lack of finance was reported by a third of respondents in a US study of perceived barriers to provider involvement in transition [134]. There are few studies reporting an economic cost evaluation of transitional care programmes although Bent reported that a young adult team approach cost not more than ad hoc services for young people with a physical disability and was also associated in increased participation in society [120]. Further research is needed in this area and further imaginative consideration of how available monies can be shared between specialties and services, acknowledging the non-categorical nature of many transitional care issues [116].

5.4 Different Perspectives of key players

In any study of transition it is imperative to **consider all perspectives** as beautifully illustrated by 2 accompanying editorials in a recent journal addressing transition for young people with diabetes [220,221]. These were entitled “Bridge over troubled water: improving the transition from pediatric to adult care. The paediatric care perspective” [220] and “Staying afloat: Negotiating the transition to adult care. The adult care perspective [221]. Telfair et al reported differing opinions between paediatric and adult providers for adolescents with sickle cell disease [9]. These differences were in relation to transition expectations and program

need especially among female providers, those practicing in urban areas and providers who treat both adolescent and adult clients in comparison with their counterparts [9].

Young people with cystic fibrosis have been reported to be less concerned than perceived by their physicians and other team members [222, 224]. Young people also differ from their parents with respect to perceived transitional care needs [225]. Amongst professionals, paediatric program directors have been reported to be more concerned than their adult counterparts [223].

Young people also differ from what attributes they consider important in doctors with studies emphasising their need for honesty, respect, confidentiality as well as competence [143] compared to similar studies of adults who in contrast, emphasised caring and communication in addition to competence [226-228].

6. EVIDENCE OF OUTCOME

Benefits of transition have been reported by several authors in terms of improved follow –up for young people with JIA [229], improved satisfaction for young people with cystic fibrosis [44, 131,], improved disease control in young people with diabetes [230], adherence to appointments post transfer [231]. Reflecting the impact of a transitional programme on transition readiness, young people with cystic fibrosis who had experienced a transition program actually preferred the adult-care setting [130] compared to those who were in a centre without such a program [225]. Results from a large multicentre study of an evidence based coordinated transitional care programme in rheumatology [232] has reported significant improvements at 6 and 12 months for adolescents and their parents compared to baseline in terms of health related quality of life, knowledge, satisfaction with health care and vocational readiness [152]. In the latter study, a centre audit also reported significant improvements in the documentation for transitional care issues following centre participation in the project [159].

7. THE WAY FORWARD

In summary there is evidence of need, process, barriers and positive outcomes of transitional care although more robust evidence is urgently needed. A summary of the major areas of research, which can build upon the current evidence base summarised in this paper, are listed in table 7. Such research must involve young people and their families and/or carers as well as paediatric and adult care providers in health, education, social services and the voluntary sector if the true picture is to be realised. Transitional care is an area ripe for development in terms of service, education and training and research. Recognition of the non-categorical nature of transition in the context of chronic illness and/or disability and subsequent sharing of knowledge and expertise between specialities will aid the “walking of the (transitional care) talk”. In so doing, we can help improve the health related quality of life of all young people with chronic illness and/or disability and enable them to reach their true potential!

Table78

Examples of Future research agendas

Model Evaluation:

Objective evaluation of “models of good practice” including economic cost

Specific service/model evaluation

Do different models of transition care produce equivalent medical and psychosocial outcomes?

Process:

Which patient characteristics (medical, social, psychosocial) identify those who need a transitional program?

Are the majority of transitional issues noncategorical?

Determine what works and for whom and in what circumstances

What constitutes transition readiness?

What defines “successful” transition?

Are there critical periods during the transition period wherein the timeliness of interventions would be more effective than others?

How do we teach young people in learning transition readiness skills?

What approaches are effective in training young people with healthcare self-care skills?

What is the content of information required by young people and their parents?

What is the role of primary care in transition?

How is this role of primary care perceived by young people, their parents and other providers?

What are the core subjects for transitional care training for health professionals?

Parents:

Does the effectiveness of parental support correlate with transition outcomes?

Is there a relationship between family characteristics and the young person’s development of transition readiness and/or achievement of transition outcomes?

Outcomes:

Can transitional care influence long-term outcomes?

Which types of programmes are most effective?

Do adolescents who participate in a transition programme do better emotionally and socially than those without a programme?

Are adolescents and their families who move from paediatric to adult care via a transition programme more satisfied with their care than those who move without a programme?

Are young adults who remain in paediatric care, less optimistic about their futures than those who move on?

What are the most appropriate outcome measures for evaluative research?

Do adolescents who participate in a transition programme have a better medical outcome than those who don’t?

General issues re: research methodology

Development of multidisciplinary research

Raise awareness within journals/funding bodies in both paediatric and adult sectors

Consideration of challenges of research within developing services and training programmes

Methodological challenges of studying an holistic process against the background of evolving adolescent development

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