

department for

education and skills



*National Service Framework for Children,
Young People and Maternity Services*

Transition: getting it right for young people

Improving the transition
of young people with
long term conditions
from children's to adult
health services

A photograph of a hospital corridor. In the foreground, a young man with spiky black hair, wearing a grey t-shirt, is shown in profile, looking towards the right. In the background, a large directional sign hangs from the ceiling. The sign is white with blue text and arrows. It lists: 'Adult Health Services' with a left-pointing arrow, 'Employment' with a left-pointing arrow, 'Further Education' with a left-pointing arrow, 'Children's Health Clinic' with an up-pointing arrow, and 'School' with an up-pointing arrow. Further down the corridor, another smaller sign for 'Children's Health Clinic School' is visible. The corridor has white walls, a wooden handrail, and a tiled floor. A gurney is parked in the distance.

Adult Health Services
Employment
Further Education
Children's Health Clinic
School

Every Child Matters - Change for Children

Policy	Estates
HR/Workforce	Performance
Management	IM & T
Planning	Finance
Clinical	Partnership Working

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Box 1

The mortality for congenital heart disease (CHD), once greatest in infancy, now arises in adult life. Today, 70-80% of CHD patients reach adult life .. and .. the mean age of death is now 25.4 years. One in five deaths was premature or avoidable (and) half occurred in those who were well or had only mild disability care is not organised properly. Sommerville, 1997.¹

It were the doctor that I saw in the children's department - he just said that I'm too old to go there any more and they were transferring me somewhere else, that's it really-and then I got a letter to say where I'd been transferred to. From a study on transition - Fiorentino et al, 1998.²

We reviewed the progress of 20 young adults [with renal disease] who had been transferred to three different adult centres at a mean age of 17.9 years having been transplanted at a mean age of 14.3 years in the paediatric unit. Eight transplants failed within 36 months of transfer, and in 7 of 20 (35%) the transplant failure was unexpected. Watson, 2000.³

In a follow-up study of 110 patients with hydrocephalus, 15 had chronic intermittent headaches, of whom four died and three suffered severe morbidity. (Of the remaining 95 patients) Thirteen died; three had raised intracranial pressure, and four died suddenly; these deaths were presumed to be related to their shunts. Up to the age of 16 there was 100% hospital follow up, but after that only 40% of young adults underwent review, including review of their shunt function. Tomlinson & Sugarman, 1995.⁴

Attendance of young people at four diabetes services averaged 94% before transfer to an adult clinic but fell to 57% two years after transfer. There was large interdistrict variation in clinic attendance 2 years post-transfer (29% to 71%); higher rates were seen in districts where young people had the opportunity to meet the adult diabetes consultant prior to transfer. Kipps et al, 2002.⁵

Preface

Transition from children's to adult health services has become an important issue in recent years for several reasons. Children are now surviving into adult life with conditions which previously would have been lethal in early childhood. Many of these are rare and obscure and until recently have been unfamiliar to those working predominantly in adult practice. Often these children and young people require the input of many medical and surgical specialists and general paediatricians play an important role in coordinating care and taking a holistic view of their needs and those of their family-but it is sometimes difficult to identify anyone willing to take on that role after transition to adult services.

The National Service Framework for Children, Young People and Maternity Services ⁶ highlighted the importance of ensuring safe and effective transition throughout children's services but also dedicates a standard to growing up into adulthood. Government policy emphasises that this is not solely a matter for healthcare professionals, since long-term conditions also have important educational, social and financial implications.⁷ Transition planning in the Health Service must secure optimal health care for the young person but it is equally important to ensure that their wider needs and their aspirations for their future are at the centre of the planning process.

The White Paper, Choosing health: Making healthy choices easier ⁸ specifically commits to action on the health needs of adolescents, including lifechecks, accessible services, the transition from primary to secondary school and into adulthood, improved access to sexual health services and joint working to meet the needs of young offenders. This is combined with a vision of increased coherence in the planning and delivery of services for young people. These principles were incorporated into the White Paper, Our health, our care, our say: a new direction for community services ⁹ and the Department for Education and Skills Green Paper, Youth Matters.¹⁰ Fundamental to the Departments' work programme is the drive to ensure that health related services, within and outside of the NHS, are equipped and coordinated to meet young people's needs long term.

The Department of Health and the Department for Education and Skills have collaborated closely with healthcare professions and other agencies, initially through a policy collaborative approach to enable accelerated implementation, to fulfil the NSF vision for better transition services (see box below).¹¹ A number of initiatives are being developed, of which this good practice guide is one. Individuals with experience and commitment to this topic are being recruited to act as “Champions”, so that best practice can be disseminated more widely. Further work is progressing too on how education and training in adolescent health can be improved.

Vision we want to see:

Young people supported to make the transition to adulthood and to achieve their maximum potential in terms of education, health, development and well-being.

Young people taking responsibility for their own health and making informed choices and decisions regarding their emotional and social development, and health and well-being both now and in the future.

Services and staff who are able to respond in a sensitive way which encourages engagement and provides high quality support for young people.

This good practice guide aims to bring together current understanding and knowledge on the subject of transition between paediatrics and adult services. Wherever possible it relies on published evidence as well as opinion and expert knowledge derived from the USA, Canada and Australia as well as the UK. Inevitably there is a particular focus on healthcare but the importance of a broad multidisciplinary approach to transition is emphasised throughout.

The guide specifically does not seek to describe the approach or approaches for improving transition for young people that are users of Child and Adolescent Mental Health (CAMH) services. While there are similar concerns about how best to improve the transitions between CAMHS and adult mental health services, there are a number of current developments in CAMHS provision, notably improving the access to services for 16 and 17 year olds and the development of services providing early intervention for young people with psychoses which requires a partnership between CAMHS and adult mental health services. In addition we are aware of a number of joint child and adult mental health services around the country, that provide a model for how transition for young people with mental health problems can work well.

Many individuals and organisations have contributed to successive drafts of this review. It would be impossible to thank them all but invidious to name just some of them; I therefore wish to express my thanks, and the thanks of the Department of Health and the Department for Education and Skills, to everyone involved in developing this work.

David Hall, emeritus professor of community paediatrics.

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A note on terminology

In this review, the term "parent(s)" also includes carers and guardians. Where appropriate, we will refer to "paediatric" services as shorthand for all specialist healthcare services for children and young people – thus it includes not only the internal medicine of childhood (the specialty usually designated as "paediatrics") but also all aspects of children's surgery and the health professionals who work in these services.

Foreword

“When I was a boy of fourteen, my father was so ignorant I could hardly stand to have the old man around. But when I got to be twenty-one, I was astonished at how much he had learned in seven years”. Mark Twain, "Old Times on the Mississippi" Atlantic Monthly, 1874

“I have found the best way to give advice to your children is to find out what they want and then advise them to do it”. Harry S. Truman, 1884-1972

The joys and perils of adolescence have been the subject of innumerable witty observations as well as a fair amount of mythology. In traditional societies, the passage from childhood to adult life is marked in a variety of ways but all of them recognise that the young person has now to take on new duties and responsibilities. In the western world, that process of transition is more protracted and often more complicated, because of the vast range of opportunities and choices now available to young people.

There are, however, increasing numbers of young people who face much greater challenges when making this transition - those who have long-term health problems which they will take with them as they grow up and become adults. In my career as a paediatrician, spanning some 35 years, I have seen some spectacular advances in the treatment of a whole variety of conditions, ranging from congenital heart disease and cancer, to epilepsy and deafness. Medical progress has allowed many children to survive and become adults, but unfortunately the treatment may only control but does not cure the underlying condition and it sometimes leaves them with a variety of secondary disabilities.

These young people frequently have to negotiate many more hurdles and obstacles than their peers when making plans and decisions about further education, employment opportunities, mobility, independence and relationships. Their task is frequently made more difficult than it needs to be, because health professionals do not adequately plan and manage the one aspect of transition which is within their control, the process of handover from services designed for children to adult oriented systems. All too often, there is an abrupt transfer from one service to another or, worse still, no arrangements are made at all. 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.

The National Service Framework for Children, Young People and Maternity Services emphasised the importance of better care for adolescence. This good practice guide, which addresses the issue of how transition can be improved, is part of a work programme being undertaken by the Department of Health and the Department for Education and Skills, with the aim of improving the quality of adolescent health care. It emphasises in particular the responsibility on health professionals to improve training and expertise in this neglected area of the health service and to ensure that young people experience a smoother and less stressful transition between clinical services. It also stresses the importance of a wider perspective that takes into account the many other aspects of transition planning, which may be as important - and often more important - than health care, and in particular highlights current thinking on the concept of "person-centred planning".

The Academy of Medical Royal Colleges has given detailed consideration to the issues discussed in this good practice guide. All the 18 member Colleges and Faculties have expressed their support for this work and are keen to collaborate in taking forward the recommendations for better training and service improvement. On behalf of the Academy, I warmly welcome all these initiatives in adolescent health care and hope that the work will attract the attention and resources it deserves.

Professor Sir Alan Craft
Chairman of the Academy of Medical Royal Colleges

Supporting Statements

Transition: Getting it right for young people

Improving the transition of young people with long term conditions from paediatric to adult services.

Support for this publication has been offered by the following organisations.

Royal College of Physicians

“The Royal College of Physicians welcomes and supports the publication of this Transition: getting it right for young people. We are increasingly aware of the clinical and personal consequences of poor links with children's services. The college will be seeking to support improvements in medical training and professional development in this important area.”

Dame Carol Black
President
Royal College of Physicians

Royal College of Paediatrics and Child Health

“The RCPCH welcomes this important guide and recognises the need to improve transition services for young people with long term health conditions.”

Professor Sir Alan Craft
President
Royal College of Paediatrics and Child Health

Royal College of Nursing

“An increasing number of chronically ill children are surviving into young adulthood. Achieving a seamless transfer is becoming one of the greatest challenges facing both children's and adult services. The Royal College of Nursing welcomes this guidance emphasising the importance of transition as a guided, educational and therapeutic process involving all members of the multidisciplinary team.”

Fiona Smith
Adviser in Children's and Young People's Nursing
Royal College of Nursing

**Royal College of Speech and Language Therapists
Allied Health Professions Federation**

"Members of the Allied Health Professions Federation (AHPF) welcome this much needed guidance, which will support the development of appropriate services to ease the transition for young people as they move into adulthood. This guidance will be an essential tool for commissioners and service providers and welcomed by allied health professionals who are integral to the delivery of high quality care for individuals across the age span."

Kamini Gadhok
Chief Executive
Royal College of Speech and Language Therapists
Member – Allied Health Professions Federation

Council for Disabled Children

"The Council for Disabled Children welcomes this guide as a step toward bringing health professionals and colleagues from other agencies together in improving the transition to adulthood for disabled young people with complex health needs."

Christine Lenehan
Director
Council for Disabled Children

Royal College of General Practitioners

"Getting it right for young people is one of the greatest challenges for all health professionals working with this age group. Having a long term illness is particularly difficult when you are a teenager - so the time of transition needs to be handled well by primary care and secondary care - this publication will help to get it right."

Dr Ann McPherson
Chair Adolescent Task Force
Royal College of General Practitioners

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Executive Summary

1. Many children and young people now survive into adult life with complex conditions that previously would have been lethal in infancy. These conditions often affect many bodily systems and many aspects of their lives.
2. Poorly planned transition from young people's to adult-oriented health services can be associated with increased risk of non adherence to treatment and loss to follow-up, which can have serious consequences. There are measurable adverse consequences in terms of morbidity and mortality as well as in social and educational outcomes.
3. Well planned transition improves clinical, educational and social outcomes for young people.
4. Successful transition planning and programmes are crucially dependent on collaboration between children's and adult services.
5. Transition should be viewed as a process and not as a single event.
6. Staff working with young people should balance the need of the young person for privacy and confidentiality, and their wish to take increasing responsibility for their own health care, with the need for their parents to have sufficient information to provide the support that these young people often require.
7. There are several models for good transition and there is no clear evidence that one is superior. Different approaches may be needed for different types of conditions according to their prevalence and the ways in which specialist health care is organised.
8. Implementing improved transition involves: recognition of the importance of the process; adequate consultation with professionals and users; flexibility in the timing of transition; a period of preparation for the young person and family; information transfer; monitoring of attendance until the young person is established in the appropriate adult oriented service.

9. 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.
10. Young people with complex disability present particular problems because often there is no equivalent adult service able or willing to take on their long-term health care and medical supervision. The need to develop a holistic approach for these young people is emphasised but it is also important for individual specialties to ensure access to quality health care for people with complex disability.
11. Suggestions for action are presented on page 36 and this has implications for a wide range of individuals and professional organisations.

1. Introduction

Transition or transfer?

The term “transfer” is often used to describe the handover from children’s services to adult services - but a “transfer” is an event. This good practice guide aims to show that the handover should be planned and managed as a process, for which the term “transition” is more appropriate. The guide suggests how this can best be accomplished in the context of the evidence base and suggests a definition of transition as follows.¹²

Box 2 – a definition of transition

Transition can be defined as “a purposeful, planned process that addresses the medical, psychosocial and educational/vocational needs of adolescents and young adults with chronic physical and medical conditions as they move from child-centred to adult-oriented health care systems.”¹²

Young people generally have considerable reserves of resilience and optimism which help them to overcome difficulties and make the move from systems and services designed for children and teenagers to those of the adult world!¹⁰ Most young people relish the prospect of becoming adults and moving on from school to higher education or work, whether or not they have any medical conditions or disability. It is important for health professionals to reinforce these positive attitudes rather than focus solely on the young person’s problems.¹³

The aims of a transition programme

As they get older, children need to be involved increasingly in decisions about matters that affect them, so that by the time they are young adults they have learned to take responsibility for their own health. That task is more complicated for those with long term health problems and the price of getting it wrong can be much higher. An increasing number of children with complex disorders that only a few years ago were fatal in infancy or childhood now survive into adolescence and adult life, presenting new and unfamiliar challenges. Young people move from a children’s or young person’s clinic, where they may have known their paediatrician

and many other staff through much of their childhood and teens, to bigger, busier adult clinics, where they are surrounded by much older patients whose diseases may be very different from their own; they are less likely to see the same doctor on each visit; consultations may be shorter; and support and advice from staff may be less readily available.

For these young people, a transition programme between paediatric and adult - oriented health services must provide co-ordinated, uninterrupted healthcare to avoid negative consequences, ranging from psychological distress and anxiety to medical catastrophe or premature death. For successful transition many young people will also benefit from help in developing skills in communication, decision-making, assertiveness and self-care, helping them to manage social, educational and employment opportunities and challenges and develop the independent living skills which underpin fulfilment and well-being. Their parent(s) or guardian may also value support, information and guidance in advocacy.¹⁴ Young people who are or have been “looked after”, homeless or otherwise socially disadvantaged have the greatest need¹⁵ but often receive the least support.¹⁶

Defining the issues - why is transition important?

Although transition can be a stressful experience, it could be argued that the stress of coping with the adult world is just part of the growing-up process and must be accepted as such. However, the evidence summarised in Box 1 and in this section shows that getting transition right does matter; many young people cannot cope with the difficulties and frustrations involved and some default from follow-up. This often results in deterioration in their condition, with serious consequences for their health and well-being and for the health service.

Good transition programmes improve outcomes Changes in morbidity and mortality following improved transition processes can only be measured with large numbers and over a long time period, but there is emerging evidence that well organised transition protocols and programmes do have measurable benefits for young people and their parents^{17 18 19} - for example, improved follow-up,²⁰ better disease control and improved documentation of transitional issues.²¹

Young people and parents have strong views about transition Young people tell us that they want a more adult, future-focused approach, with long term goals, more control and increasing self-management^{22 23 24} during their adolescent years. They feel that paediatricians tend to treat teenage patients like children and talk to their parents instead (see quotes²⁵ in box 3³).

Box 3 - comments from young people about communication.

- I think that you should give the information to teenagers actually instead of talking to parents all the time . . . I think it is important that young people are told as soon as possible what their medication is, what treatments are, what's happening with them because otherwise you go at 14 and 15 years old and haven't got a clue what drugs they're on or anything like that.
- I don't know why they ask parents, it isn't parents that have got the arthritis.
- You get really fed up of other people making the decisions because it is your body, and you want a say in it.
- I'd like to have talked to other teenagers about the problem, because you're just sitting in a waiting room with 80-year-old women, and I'm not being funny but you know you felt like a freak.
- If you've been with them a long time, the same person, you get a little bit of attention, and you do ask more questions, but . . . when you're jumping from pillar to post, like I was seen by six doctors in one year, then I just didn't want to talk to them, but if you stay at the same doctor you tend to get a bit closer, to open out.

³ Reproduced by permission of the publisher

2. Planning Transition Services

Improving transition needs time, resources and commitment²⁶– but these are tiny compared to what was invested in the health care of each child and young people throughout their childhood. It makes sense to ensure that this is not wasted because of poor transition.

The following issues have been identified as being important in the planning of transitions services.

1. *Address professional and managerial attitudes* The biggest single obstacle to progress is in attitudes. Recognising that transition is a process, not an event, is the fundamental change of attitude that is required.
2. *Recognise the differing perspectives of paediatricians, physicians and GPs* Handing patients over to another service is difficult for paediatric staff who become attached to their young patients over many years.

They worry about their young patients growing up and moving on more than their adult-oriented colleagues - and often more than the young people themselves.^{27 28} As many of the long term conditions that affect their patients are rare and, until recently, virtually unknown in adult practice, they may worry about a lack of expertise among their colleagues in adult services. Specialists working in adult services share this worry but find it difficult to focus on the particular needs of these young patients when they are overwhelmed with large numbers of older adults, many of whom have multiple pathologies. Adult clinic staff generally treat their young patients like adults and expect them to take responsibility for their own health care; but they may forget that many young people who have grappled with ill health and disability for much of their lives may be immature and vulnerable, and that parents and other people continue to play a key supportive role for many young people with chronic illness.

There are also difficulties for GPs, who may be consulted by young people during transition and asked to take on a wider role. Paediatricians are often tempted to deal with every minor ailment in their patients with complex problems, but this marginalises the general practitioner, so that he or she is poorly equipped to take over more of the young person's care when they leave paediatrics. Information sharing with the GP and other primary health care staff is often inadequate.

Preventive and health promotion staff in the community may have had little or no opportunity to contact these young people who may miss out on services like immunisation or advice on healthy lifestyles and sexual health.

3. *Establish dialogue between clinicians, management and commissioners and other agencies* Commissioners need to be well informed about transition. Multi-agency links are particularly crucial where the young person's health problems are likely to result in significant disability. Where NHS commissioners with their local authority partners purchase packages of care for young people with complex needs, this should help to ensure that future service and support requirements are already agreed by the time the young person is ready for transition.
4. *Appropriate environment* Adolescents do not feel comfortable in wards or clinics where they are surrounded by small children or elderly adults. Ideally, an adolescent in-patient unit should be provided but this will not always be the case and flexible approaches should be available.²⁹ Out-patient clinics should have a décor appropriate to this age-group and these requirements should be incorporated in planning (Box 4). Even when resources are not readily identifiable, including these environmental issues in policies, plans and procedures ensures they are not forgotten.³⁰

Box 4 – appropriate environment

It's all for babies and kids . . . when you get to your teens, you don't want to see the teddies and rattles and dolls. (teenager)

5. *Consultation with users - young people and their parents*³¹ There is ample research evidence about the views of young people regarding generic transition issues. For service providers, consultation with users should focus mainly on local issues and establishing a quality monitoring or feedback process. Young people soon recognise tokenistic gestures and expect that action will follow consultation. They should also be encouraged to become "expert patients"^{32 33} so that they understand their own condition and, in some cases, contribute to the education of healthcare staff and to service improvement.

The principles of good transition from the user perspective have been summarised in a number of publications, and are outlined in Box 5 below.^{34 35}

Box 5 - Good transitions – what young people say they want.

- Active management of transition - consider the timing; plan early and prepare for leaving children's services and arriving at the adult service.
- Take into account how attitudes, thinking and behaviour vary between individual young people.
- Involve young people in service design and delivery: provide opportunities for young people to ask questions, express opinions and make decisions.
- Provide accessible information about services; share information between services; ensure multi agency working, co-ordination and accountability across different organisations within the public sector and voluntary organisations.
- Stress the importance of a trusted adult who can challenge and support them, act as advocate and help them to develop self-advocacy skills.
- Establish a shared philosophy between adult and paediatric care.
- Adopt an individualised honest approach.
- Address loss of continuity of care at transition; ensure new relationships are established.
- Train professionals in adolescent health in both paediatric and adult sectors.

6. *Agree a policy on timing of transfer.* There is no one "right" time or age for transition (Box 6). Rigid age limits defining children's and adult services are undesirable and there is no fundamental reason for them other than financial convenience. Similarly, there is no justification for using chronological age as the only policy criterion when deciding whether a young person should be admitted to a children's or an adult ward. The Trust policy – and commissioning and funding arrangements - should stress flexibility about the age of transition and the way the young person is managed after transition to adult services.

Box 6 – comments on age of transition

- All we got on her 16th birthday was, three days later, a letter which says 'You are now over 16. You're discharged'. (Parent of young adult)
- You're so connected up with the physios and people like that aren't you? . . . you're involved with the hospital from when they're little children, right up until they're 18, and then it's just cut like that. (Parent of young adult)
- The children's ward wouldn't accept her because she was over age 16, the adult ward wouldn't accept her because she was under 18, and so we had hell-of-a-game trying to find a ward for her and in the end she ended up going on a geriatric ward for the night. (Parent of teenager).
- 16 is an age when there is lots of other change. When moving schools, it happens at the same time to everyone and changing schools is hard enough - but changing consultants and hospitals is even harder because you are doing it on your own and doing it because you are suffering from a serious illness (young person attending conference).

Timing must depend on the developmental readiness and health status of the individual adolescent as well as the capabilities of the adult providers. Time since end of treatment may be important in some situations and transition should, where possible, be during remission rather than relapse or when disease is active.

Chronic illness and treatment may cause both physical and psychological delay in maturation. Ideally, children and young people's services should be prepared to provide health care for young people until they have largely completed the developmental tasks of adolescence. The perspective of other agencies is equally important; for example, in school the formal transition planning process starts at age 14 (year 9) and it is helpful to embed medical transition within the broader context of growing up and moving on, incorporating health action plans where appropriate.

7. *Set up a preparation period and education programme for the young person and parent: Identification of the necessary skill-set to enable the young person to function in the adult clinic* The young person must acquire the knowledge and skills to function in an adult service, largely independent of parents and staff, before they are transferred.³⁶ Transition checklists are useful for identifying such skills.³⁷

Paediatricians and their associated teams should begin to introduce the concept of transition long before it becomes an issue. Naturally the precise age when this is appropriate will vary according to the condition and the family but although it is obvious to the paediatrician that the young person will eventually need to move on to adult services, this may not occur to the family unless they are told. Preparation should begin by mid-adolescence, at the latest, when discussions with the young person themselves should re-address their understanding of their disease, their treatment and its possible side effects, and most importantly, how to seek help from professionals in the main agencies, as well as developing social independence, using community facilities etc.

As part of this programme, the doctor should introduce the concept early that the young person could be seen by themselves in clinic visits or with someone of their own choice, with parents invited to join the session later. A schedule of likely timings and events is discussed with young people in early adolescence, and they are involved in developing detailed timings for their own transition; however, parents are often the main source of support for their offspring, particularly where the young person lacks the maturity or cognitive ability to cope with complicated information. The parent needs to know what the young person has been told, while maintaining confidentiality. Leaflets and material about "moving on"

details of the adult service should be provided in clinic settings from early adolescence. Additionally, 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.

What happens in the consulting room - the triad of communication between parent, young person and professional - is key. Doctors often think the parents inhibit the child from speaking for themselves – but parents complain about doctors who ignore the young person and only speak to the parents (Box 7).

Box 7 – communication and continuity – users' views

- They [the medical notes] were lost in transmission between the two hospitals, which meant cancellations of appointments . . . In the last 4, 5 years, I've seen Dr . . . once. (Young adult)
- My parents are quite cool; they ask 'Do you want us to come in?' and I say 'No. I'd rather go in by myself.' because I feel that I achieve more by going in and talking to [the consultant]. If they're there, [the consultant] just ignores me, talks to them and I just come out and don't feel anything's been achieved. (Teenager)
- You've got to start getting teenagers going to their own clinics, and doing their own thing, by the time they get up there [adult service] without their parents or they just won't go. (Young adult)

8. *Plan a co-ordinated transfer process* The way transfer is organised depends on the model of care in use locally - transition models and their relevance to various specialties are discussed in the next section on page 25.

If transfer is to be to a distant clinic, adolescents should receive a detailed outline of the adult program around a year before the anticipated transfer date, and should undertake at least one visit to the adult clinic, preferably with parents and a trusted carer. A personal introduction to the adult environment and staff should be arranged, and a return visit to the children's or young person's clinic organised to discuss any concerns before formal transfer. A co-ordinated process requires a co-ordinator. This role can be undertaken by any member of the multi-disciplinary team or the lead professional.⁹ In speciality clinics, however, clinical nurse specialists or therapists may be best suited to run transition programmes.

9. *Identify interested and capable adult services* A transition programme can only be successful if organised with the active participation and interest of the receiving adult service. Those seeking to set up a transition program must explore the economic and research consequences of the loss of patients from paediatric follow-up and the increase in patient numbers for the adult service. The development of close and frequent clinical and academic links between the services can ensure that the collaboration is beneficial to both services and that patients are not lost to research follow-up.
10. *Identify a co-ordinator* 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. The co-ordinator might be one of the specialist team, the general practitioner, the specialist nurse, the lead professional or a previously designated key worker or some other person – whoever it is, they will need sufficient time to take on the tasks of co-ordinating the young person's programme.

11. *Consider Information transfer* Young people with long term conditions often have bulky medical records - it can take several hours to produce a multi-disciplinary summary of their history and management in a way that will be useful to someone taking over their care.³⁸ Problem oriented records, giving copies of key letters and summaries to the young person to keep in a Personal Health Record, Health Passports and ensuring that GPs are kept fully informed are helpful strategies.
12. *Monitoring and "fail-safe" mechanisms* A formalised transition checklist is helpful. There must be a failsafe mechanism that ensures that the young person is regularly attending the adult clinic and has not defaulted or failed to attend or been lost to the system - he or she should not be discharged finally from the children's or young person's clinic until it is certain that their care has been successfully transferred. It may, for example, be helpful to monitor "did not attend" instances for the second appointment at the adult clinic after transition.
13. *Ensure primary care involvement* Primary care staff should be invited to participate in transition planning and may be able and eager to coordinate the young person's future medical care. There may be a benefit in primary care services taking a lead in the co-ordination of care for young people with a number of long term health conditions, or where there is currently no obvious adult service to be part of the transition arrangements. Many PCTs are already developing specific community based services for people, including young people, who have long term conditions and are frequent users of hospital services.
14. *Negotiate administrative support* Institutional and management support need to be assured at both ends of the transfer chain. Casual agreements between doctors, while easy to set up, are prone to failure. Policies and transition protocols need to be agreed at appropriate meetings and receive management support. Resources such as administrative and secretarial support must be available to ensure the efficient organisations of appointments and the transfer of medical records.

3. Models of Transition

The most prevalent model for a transition service is not transition at all, but rather a transfer of young people to what looks like the most relevant adult clinic - or, worse still, discharge from the children's or young person's clinic with instructions to ask the GP for a referral to adult services. Many different models of transition have been described and studied though no single approach has been shown to be superior.³⁹

The models include:

- A dedicated follow-up service provided within the adult setting without a combined paediatric-adult clinic and with no direct input or continuity from paediatric services.

This is the simplest model but, in order to work well, there needs to be a good co-ordinated transition process between them (e.g. involving nurse specialists taking young people to the adult clinics and meetings between the paediatric and adult clinic staff to plan coordinated care).

- A "seamless" clinic which begins in childhood or adolescence and continues into adulthood, with both child and adult professionals providing ongoing care as appropriate.⁴⁰

This joint approach allows patients to benefit both from experts in paediatric diseases and the appropriate management of fertility, cardiovascular health, psychological disorders and other "adult" problems. It also allows both groups of specialists to go on learning from each other and from the patient's experiences. The duration of joint care should vary from patient to patient and between specialties. For instance, cancer follow-up may need to continue for years whereas diabetes may need a shorter period of transition.

- Life-long follow-up within the paediatric setting - this sometimes happens by default in disability services, for example with cerebral palsy, Duchenne muscular dystrophy or Down's syndrome.

This approach ensures continuity of care and may sometimes be appropriate in conditions with a limited life expectancy, but may make it more difficult for the young person to access expertise on, for example, contraceptive and fertility problems and diseases of ageing, or on vocational and benefits issues, and to develop more appropriate independent living alongside their peers.

- A generic “transition team” within a children’s hospital – such as the model developed by the “On Trac” team at British Columbia Children’s Hospital, Vancouver. It involves having 1-2 dedicated nurse specialists who can ensure that all young people in the different specialities go through appropriate transitions. They have developed excellent literature and diaries - ideas that could be developed for UK use.
- Generic “transition co-ordinators” for larger geographical regions, as have been recently developed by the Department of Health in New South Wales, Australia, to cover a wider area.⁴¹ This model may be appropriate for conditions which are relatively rare, or for co-ordinating links between Children’s Hospitals and local General Hospitals.

4. Specialty specific issues and Young People in special circumstances

There is no single service model for transition, as there are many different conditions. Some conditions, like diabetes, are common both in children and in adults and many district hospitals already have close links between services⁴² - although even for these common problems the quality of transition varies to an unacceptable degree.⁴³

Transition for young people with congenital heart disease (CHD) is improving with the emergence of cardiologists specialising in CHD. Links between paediatric cystic fibrosis services and specialist adult respiratory physicians facilitate transition for these young adults. Late-effects clinics for the long term follow-up of young people who are cancer survivors are being developed.

For other medical specialties, for example inherited metabolic disease, chronic infectious diseases (such as HIV/AIDS) and immunology, or renal disease, the picture is much more varied.⁴⁴

A particular difficulty arises when the young people's specialty service is at a tertiary centre but the adult counterpart is at secondary or district level, so that the young person may have to adjust to a different hospital as well as a new service and team. There are also problems in handover for young people with conditions normally cared for or monitored by general paediatricians - for example, multi-system disorders like neurofibromatosis, in which life long monitoring for a wide range of problems may be required, or chronic fatigue syndrome, which requires a holistic approach to care and rehabilitation.

1. *Chronic fatigue syndrome / myalgic encephalopathy (CFS/ME)*⁴⁵ In practice, CFS/ME has its peak prevalence in mid to late adolescence. Transition presents a particular problem because the trend to specialisation within adult medicine means that there are few "general physician" equivalents to the general paediatricians who usually manage these patients. Individual reports suggest that the potential role of the general practitioner as a "broker" of specialist care is not always fulfilled. Recent Government initiatives seek to establish more effective models of multi-disciplinary care and better transition for CFS/ME.

Recent Government initiatives are establishing centres of expertise to develop clinical care (including better transition), and to support clinical research and expand education and training programmes for healthcare professionals.

2. *Surgical specialties* Some young people with surgical problems may experience continuity of care from the same consultant from childhood into adult life, particularly in those specialties where training includes all age groups. Even if the young person remains under the care of the same consultant, new financial and commissioning arrangements may be needed if the surgeon's paediatric and adult practices are in different hospitals.

With increasing surgical specialisation, transition is becoming a more important issue. For example, a number of eye conditions require active continued management from childhood through to adult life, including congenital cataract, congenital glaucoma, retinitis pigmentosa and other inherited retinal diseases, corneal dystrophies and chronic uveitis. Many of these young people have other disabilities as well. Children with spina bifida need coordinated care involving neurosurgeons, orthopaedic surgeons and urologists but there are major obstacles to providing this for young adults.⁴⁶ Gynaecologists have to deal with young people growing up with genital anomalies or intersex conditions and may be called on to give advice to young people with complex disorders on menstrual problems, contraception and fertility.

Neurological disorders and disabilities

These young people are the least well served as there is often no service available to take over their care when they leave paediatrics. New approaches are needed⁴⁷ and it should be the responsibility of all specialties – not just of those with a special interest in disability or rehabilitation - to consider how the care of these young people can be improved. This issue is discussed in more detail on page 28.

What is neuro-disability? The category includes people with disparate conditions: movement disorders such as cerebral palsy and muscular dystrophy; learning difficulties and disabilities;⁴⁸ autistic spectrum disorder; sensory impairment; static or slowly progressive neuro-degenerative disorders; young people with acquired brain injury; spinal lesions such as neural tube defects; hydrocephalus; difficult or intractable epilepsy syndromes that differ from those seen in adult neurological practice.

In general, young people with any of these problems receive good care from a child development team or service in the pre-school years. The quality of care is more variable once they are at school but they generally get good support from the education service, social services and sometimes voluntary organisations.⁴⁹

Palliative care services for children and young people can offer additional help for those with severe disability or high care needs - a seamless transition to adult palliative care services is essential and should be reflected in services commissioning.⁵⁰ In the case of deteriorating conditions such as Duchenne muscular dystrophy, a health advocacy role is needed, for example in negotiating housing modifications or a Disabled Facilities Grant.⁵¹

A variety of needs Disabled young people have a wide variety of social, educational, housing, employment and financial needs,⁵² which often are more pressing than their specifically medical problems.⁵³ Many of these young people do not need ongoing healthcare, other than for illnesses and complaints for which they can see their general practitioner. Some individuals, however, do have a continuing need for health professional input. Challenging neurological problems, such as intractable epilepsy, may need regular review. It is said that there are now around 6000 technology dependent children in the UK⁵⁴ - only a minority of these are old enough to have entered the transition stage, but it is clear that their medical and care needs as young adults will present a considerable challenge. Physiotherapy, occupational therapy and speech and language therapy may be required but are often less available for disabled adults, even though their condition may have deteriorated since their school years. Supply, replacement and maintenance of mobility and communication equipment may be difficult to obtain.

Young people with neuro-disability often have multiple problems needing the involvement of many other specialists, yet few consultants or GPs feel equipped to take on this role. Hospitalisation of a severely disabled young adult can be a stressful experience for all concerned, yet adult wards may be unsympathetic to their reliance on the parent or carer. Although there are excellent models⁵⁵ and examples of well organised services, it is often difficult to identify anyone willing to take on the task of coordinating medical care for these young people and provide them with the kind of holistic medical advice they need. The nature of their disability often makes it very difficult for them to access mainstream specialist medical services which find it difficult to cope with their communication problems and with the additional time it takes to assess their presenting complaints. Furthermore, disabled people have at least the same risk as anyone else of general health problems, such as cardiovascular disease, mental illness and cancer, but they are less able to access preventive health care or to get advice at an early stage for worrying symptoms or signs.^{56 67}

Health care The health care of a young person with a disability should be integrated with a holistic person-centred plan (page 32). Health care could be led by:

- a consultant in rehabilitation medicine and their team;
- jointly, by a rehabilitation consultant and paediatrician;
- a specialist nurse for transition;
- an occupational therapist;
- a general practitioner with a special interest in disability;

Multi-disciplinary multi-agency teams can provide services for young adults with disability and some have special expertise in various forms of disability:⁵⁷

- > Those with learning disabilities may come under the care of a community learning disability team, which brings together a range of disciplines, often including a psychiatrist with a particular expertise in learning disability;⁵⁸ this interest may extend to other forms of disability.
- > Young people with visual or hearing impairment continue to need specialist medical services and also have particular needs with regard to social care, employment, mobility and mental health problems.
- > Young adults disability teams – some of these have a remit to support young people through transition from children's to adult services and have been shown to be no more expensive than ad hoc services.⁴⁷

Whatever approach is adopted, the concepts of Key Worker and Lead Professional are important. Key Workers can make a valuable contribution to the coordination of all aspects of care for individuals with disability.⁵⁹ In a transitional care programme in rheumatology, local transition programme coordinators were reported by young people to be more important than paper-based informational resources.³⁷

5. Knowledge and Skills required by professionals

Communication and consultation skills

By far the most important issue in the eyes of young people is communication (Box 3). Working with adolescents needs different consultation skills from those needed for children or adults in addition to the technical knowledge relevant to each individual specialty.⁶⁰ Young people also expect their specialist team 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. Psychological and social difficulties are common even among otherwise healthy adolescents, and the frequency is increased among those with long term or chronic disorders. Depression, anger, risk taking behaviour and non-adherence to treatment are all important issues. It is important for professionals either to address these or to have access to colleagues with the necessary expertise. Training in these areas for both children's and adult health care staff will be crucial in the development of transitional care programmes.^{61 62} Several educational programmes in adolescent healthcare have been shown to improve knowledge and skills.^{63 64 65 66}

*The duty not to discriminate*⁶⁷ Disability is everybody's business: doctors and other health professionals in every discipline may be consulted by disabled people. The service offered must take account of the specific problems that make consultation more demanding and more time-consuming – for example, difficulties with communication due to hearing or speech disorders, inability to explain symptoms clearly because of intellectual impairment, or simply being unable to get undressed quickly for physical examination. The Disability Discrimination Acts of 1995 and 2005 place a duty on businesses and organisations, including education providers, not to discriminate against disabled people. There will also be a duty to promote equality of opportunity for disabled people. The legislation has important implications for health care commissioners and providers.

The role of parents and carers Notwithstanding public policy commitments to employment and independent living, and the recognition that these are important for young people with long-term conditions, the reality is that many of them are living at home with one or both parents.⁶⁸ When giving advice or explanations to the disabled individual and an accompanying carer, the health professional may have to balance the individual's ability to understand with his or her right to privacy and confidentiality.

*Teamwork is important*⁶⁹ - successful models of transition often depend on someone other than doctors to offer advice and information to the young person, to ensure that they know all the options, are put in touch with other agencies as needed, and oversee the process of transition until the young person is safely established in the appropriate adult services. They may value guidance, or pointers to sources of information, on-going health support at college, education, careers, leisure options etc.

A holistic approach to transition planning

The focus of this good practice guide has necessarily been on transition within the health service, but young people are not only making the transition to adult health services. They also have to manage transitions within education from pre- to post-16 provision, whether that be moving into a school sixth form or from school to further education or training. They may be leaving education and going out to work, leaving home to move into their own accommodation, or moving on to adult social services provision. 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 nature of the young person's condition and disability. For example, they may need to 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.

Connexions The chances of successful transitions for these young people are greatly enhanced by a multi-agency approach informed by the young person's need for service provision which makes sense as a complete package.^{70 71}
*Connexions*⁷² can act as the lead in promoting this multi-agency approach (Box 8).

Box 8 – Connexions

Connexions is, the advice and guidance service for young people aged 13 -19 and available to young people with learning difficulties and disabilities up to the age of 25. It provides support to all young people with additional needs during their transitions to adulthood. For those with learning difficulties or disabilities who are thinking of going on to further education or training, Connexions can do assessments of their needs and the provision which will be required to meet their needs under Section 140 of the Learning and Skills Act 2000. Connexions has an important role in transferring information about a young person's needs but colleges and potential employers may require advice about a disabled young person's health and any risks but such advice can be difficult to obtain. The National Service Framework for Children, Young People and Maternity Services sets out the need for and composition of a multi-agency Transition Group to ensure that all the available resources are utilised for young people with disabilities.

Young people with disabilities or long-term conditions may have a statement of special educational needs (SEN). For these young people a statutory transition planning process begins during year 9 of compulsory schooling around the age of 14 years - Connexions must attend the Year 9 'transition' review which results in a Transition Plan. This should be a multi-agency meeting if the young person's needs call for provision from a number of agencies. The SEN Code of Practice gives Connexions responsibility for overseeing implementation of the Transition Plan, co-ordinating its delivery with relevant agencies. A national programme to introduce a person-centred approach to transition planning is being introduced 2004-2007.

The SEN Code of Practice also encourages (but does not require) schools to consider transition planning for young people with SEN and disabilities who do not have statements.

A multi-agency approach for a range of young people with special needs and disabilities will be at the core of transitions guidance which is being drawn up by the Council for Disabled Children, in association with the National Bureau for Students with Disabilities, on behalf of the Department for Education and Skills. This will set out the roles in transition for professionals in children's and adult services and give guidance on issues such as person centred approaches and joint planning. The guidance will be published in the summer of 2006.

Children in Special Circumstances

Young people in special circumstances are at risk of achieving poorer health outcomes than their peers. This group includes looked after young people and care leavers, and those made vulnerable by circumstances (Box 9). Access to services can be a particular problem for young people in special circumstances as set out in the Children's NSF.⁷³ Their care requires a high degree of co-operation between staff in different agencies. They tend to be "lost" between agencies and are therefore not in receipt of services, even those that are universally provided. Transition requires a high degree of co-operation between key agencies, with a designated key worker or lead professional.

Box 9

examples of "Special Circumstances" which affect transition planning

- Young people whose families are living in temporary accommodation.
- Young people who have run away from home or care.
- Young people exposed to domestic violence, family conflict and/or family breakdown.
- Young people who suffer from sexual exploitation.
- Young people whose parents have specific health needs, for example, those with mental health problems, drinking or substance misuse problems.
- Young people who have been excluded from school, or who are truanting.
- Young people who are not in education, employment or training.
- Teenage parents.
- Young people from some ethnic minorities.
- Young people who are refugees or seeking asylum.

Person-centred planning

The Youth Cohort Study⁷⁴ shows that, despite the statutory support and transition planning available to them, by the age of 19 a quarter of young people who were identified as having SEN and disabilities at school were not in education, employment or training (NEET). These young people will have had aspirations for their adult lives in the same way as young people without SEN or a disability and their failure to achieve satisfactory outcomes emphasises the need for appropriate

support during the years of compulsory schooling which helps them face the challenges of the transition to adult life.

It also highlights the need for the “person centred” approach to transition planning which is based on the young person's aspirations and not on what providers find it convenient to offer. “Valuing People” gives guidance on person centred planning as does the Information Pack for Transition Champions, published as part of the Valuing People strategy. The Department of Health and the Department for Education and Skills have been funding 70 local authorities to introduce a person centred approach in the statutory transition planning process under the SEN Code of Practice.⁷⁵ This work will extend to all local authorities from April 2006.⁷⁶

The parents' and carers' perspective When disabled young people leave school, where they were supported by dedicated teachers backed up by health teams, they find that the services for young adults are overstretched or non-existent. All too often their parents are faced with the stark reality that, in spite of increased commitment to support adults with disability in the community,⁷⁷ their offspring have little prospect of ever achieving independence and they must plan for the young person's needs far into the future⁷⁸ (Box 10) and into their own old age.⁷⁹

Box 10 – transition and disability

- Disabled young people and their families often find the transition to adulthood both stressful and difficult. For many, there has been a lack of co-ordination between the relevant agencies and little involvement from the young person. Some young people are not transferred from children's to adult services with adequate health care plans, which results in their exclusion from adult services. This is likely to affect young people with severe learning disabilities and complex health needs in particular. Starting adult life should be a time of opportunity for young people. “Valuing people” 2001.⁸⁰
- The Mental Capacity Act 2005⁸¹ provides a statutory framework for people who may not be able to make their own decisions for example because of a learning disability, an illness ... or mental health problems. It sets out who can take decisions, in which situations, and how they should go about this.

6. Suggestions for Action

1. The National Service Framework for Children, Young People and Maternity Services (Standard 3 – markers of good practice) requires each PCT and NHS Trust to identify a senior lead for children and young people to ensure that their needs are at the forefront of local planning and service delivery. This person should be made aware of the need for improvement and organisational policies for Transition, as part of the implementation of the NSF.
2. Children's and adult health services should agree the best way of measuring the effectiveness of transitions arrangements, and whether agreed policies and protocols are being implemented. One example of an indicator used to do this is to measure over time the "did not attend" (DNA) rate for young people at their second adult service appointment.
3. There is a poor understanding currently of the medical consequences for young people on making the transition to adult health services. This is an area that would benefit from specific clinical audit projects. Clinicians and a range of health and other professionals could contribute to both the medical, personal and social outcomes of transition arrangements.
4. The Academy of Medical Royal Colleges and other bodies should encourage each of their member Colleges to ensure that transition planning and services for young people are part of their agenda for setting quality standards and for continuing professional development.
5. The Royal College of Nursing, the Nursing Midwifery Council, and the professional bodies of the professions allied to medicine similarly need to ensure that this is part of their professional training and development and to build on the excellent work already done in particular by the Royal College of Nursing (for example, in their report "Adolescent transition care-guidance for nursing staff" RCN 2004).
6. As many of the issues about adolescent health care and transition are generic, a shared training resource should be developed, which could be at least partly web-based, and should draw in particular on the acknowledged expertise of some individuals of the Trust for the Study of Adolescence and the National Children's Bureau, and the Royal Colleges of Nursing, of General Practitioners and of Psychiatrists.

7. Voluntary organisations should encourage the parents and young people who make up their membership to raise their expectations with regard to the process of transition and the way it is managed; they should gather examples of good and unsatisfactory practice and disseminate these and, where possible, take on the role of educators of the professions as “expert patients”.
8. The NHS Research and Development programme and other research funding organisations should encourage and support a research agenda in adolescent health and transition.
9. There are examples of excellent co-operation between a wide range of professionals and organisations in the UK in the development of transitions services. Partnership working with Youth Services, and Connexions services is seen as particularly helpful where those links have been made and these links could be further developed.

Annex A - Resources to Support Transitions: Getting it Right for Young People.

Good Practice examples

The Department of Health has collected examples of good practice from services in England over the last year.

These are available on the DH website at the following
www.childrensnscasestudies.dh.gov.uk/children/nsfcasestudies.nsf

The list below is a summary of the title or subject of the good practice examples relevant to improving transition for young people with long-term health conditions.

1. Transition of young people to adult services who have "common adult, rare childhood" conditions, e.g. Inflammatory Bowel Disease, Chronic Arthropathies.
2. Transferring teenagers with congenital heart disease to the adult congenital cardiac service.
3. The under detection of childhood Urinary tract infection and reflux nephropathy causes significant problems for some children in later life. Approximately 20% of patients undergoing renal transplantation at any time in the UK are the result of damage cause by childhood UTI.
4. Poor HCC review of adolescent services.
5. Need for (i) skills training in independence and (ii) peer support for young people with chronic rheumatic conditions.
6. Need for the development of transitional care services in adolescent rheumatology in the UK [1].
7. The first controlled trial of transitional care in any chronic illness, funded by the ARC (www.arc.org.uk) and conducted on behalf of the British Society of Paediatric and Adolescent Rheumatology.
8. In 2002, a hospital-wide audit of transitional care was conducted. Only 3 of 38 relevant specialties/clinical areas had a written transition policy for young people with chronic illnesses and/or disability, now an NSF standard.
9. Adult follow up of childhood cancer survivors.

10. Lack of dedicated facilities for adolescents to have preparation for transition to adult services.
11. Recognition to work effectively together within the health economy as a precursor to providing integrated services for children and to adopt a whole systems approach to care working across organisational boundaries. Able to identify this as fundamental to working effectively as a precursor to Children's Trusts.
12. Birth trauma and post traumatic stress disorder following childbirth.
13. Maternal Mental Health support for mothers with postnatal depression (mild to moderate symptoms).
14. Young adults with very complex health/palliative care needs and learning disabilities were becoming trapped in children's services due to adult district nursing and learning disability teams feeling unable to safely cope with their needs.
15. Young people remaining in a paediatric hospital after they had reached 18 years of age. Young people leaving different specialities within this hospital at varying ages often with little preparation for coping with adult care.
16. Recognition of difficulties experienced by young people and families in accessing adult services. This applies particularly (in our local area) to young people with physical disabilities as those with learning disabilities are served well by a designated service.
17. Development of a service for young people with diabetes that recognises the transition to adulthood by shifting the emphasis to self empowered and self directed care.
18. The large majority of patients with cystic fibrosis now graduate to adult services which are not geared to the intensive input required for this condition. Transition of young people with complex disabilities from paediatric services to adult services.
19. Liaison between Community CAMHS, inpatient Adolescent Unit, and adult services when a young person is being discharged from inpatient CAMHS to adult services, having been initially referred by community team.
20. Teenagers who have profound and multiple learning disabilities from special schools and their families need to feel that there is a clear handover from paediatric therapy to adult services.
21. Staff wished to review the transition from the children's diabetes service to the adult service.

22. Adult health services may be diagnosis specific.
23. CAMHS in Durham and Darlington ended at 16 yrs with adult mental health starting at 18yrs.
24. The continuation of a number of very specialised children's tertiary services are increasingly vulnerable as a consequence of changing clinical practice, impact of the consultants contract, EWTD and workforce shortages. Providers need to identify new solutions to old and new problems which are sustainable.
25. Transition process from paediatric to adult cystic fibrosis (CF) care was not streamlined, or standardised or multidisciplinary.
26. Care coordination of children and young people with complex needs with or without disability.
27. Further education colleges approached school for pupils with physical disabilities, concerned about incomplete information, pupils leaving school unprepared, placements breaking down (no occupational therapy input due to service pressures).

Annex B – Additional resources to support services development for transition for young people with long term health conditions.

Transition Resources

National Service Framework for Children, Young People and Maternity Services website. Follow the links to the Transitions section
www.dh.gov.uk/childrensnfs

Every Child Matters – Change for Children
Lead Professional
www.everychildmatters.gov.uk/deliveringservices/leadprofessional

Adolescent Transition Care. Guidance for Nursing Staff (July 2004)
www.rcn.org.uk

Bridging the Gaps. Health Care for Adolescents (2003).
www.rcpch.ac.uk

You're Welcome Quality Criteria. Making health services young people friendly (Oct 2005)
www.dh.gov.uk/publications

Transitions: Young Adults with Complex Needs (Nov 2005)
www.socialexclusion.gov.uk

Publications from British Columbia in Canada, in the Kids, Teens and Families section of the website.
www.bcchildrens.ca/default.htm

Website with resources for planning transitions. Melbourne Australia. Linked to the State of Victoria report on Transition.
www.rch.org.au/transition
www.health.vic.gov.au/subacute/transfer_young.pdf

Council for Disabled Children – transition newsletter with many different resources in the newsletters.
www.ncb.org.uk/cdc

Youth friendly publication on transitions.
www.transitionpathway.co.uk

Birmingham Adolescent Rheumatology website.
www.dreamteam-uk.org

Website for people to talk about their health experiences, including young people.
www.dipex.org

Chronic Fatigue Syndrome (CFS) and Myalgic Encephalopathy (ME) exemplar
www.dh.gov.uk/assetRoot/04/09/81/25/04098125.pdf

Planning and funding investment for people with CFS/ME
www.dh.gov.uk/PolicyAndGuidance/OrganisationPolicy/FinanceAndPlanning/FinanceArticle/fs/en?CONTENT_ID=4049222&chk=fMp9al

NICE to produce guidelines for the management of CFS/ME
www.dh.gov.uk/PublicationsAndStatistics/PressReleases/PressReleasesNotices/fs/en?CONTENT_ID=4073855&chk=WbmPGH

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