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Transition: moving on well

A good practice guide for health professionals and their partners on transition planning for young people with complex health needs or a disability

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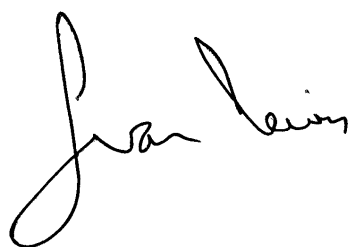
Ministerial foreword

Young people and their families frequently tell us how worried they become as the young person moves towards the time when they leave children's services, and tell us about the difficulty of living with the uncertainty of what support they will receive in future. They describe it as a 'cliff edge' – moving from firm ground where, in the NHS, they receive coordinated care across different medical specialties from a multidisciplinary team that knows the patient well, to the unknown, where there may be limited expertise in the adult service because the condition is so rare or provision is not focused on the needs of young people.

Adolescence can be a difficult time for any young person but even more so for those who have ongoing health needs. We owe it to all families to work with them to prepare for the change in care and make sure that adult services have been involved in those plans and are ready to take over the support.

We know, and have seen some wonderful examples, of children and adult services working together to prepare the young person and their family. This good practice guide builds on what is happening in some areas and will be of use to those who are developing their services. It is intended specifically for health professionals and their partners. It has a particular focus on young people with a neuro-disability because they are the group that is currently least well served, but the principles can be applied for any young person with ongoing complex health needs.

The guide builds on the guidance *Transition: getting it right for young people*, published in 2006, and *A transition guide for all services*, published in October 2007. It also supports the initiative for a Transition Support Programme in the *Aiming high for disabled children* report.



Ivan Lewis MP, Parliamentary Under Secretary of State for Care Services



Andrew Adonis, Parliamentary Under Secretary of State for Schools and Learners

Endorsements

Adolescence is a period of significant change for any young person, even more so when they have ongoing health problems, when care needs to continue within the adult health and social care setting. The manner in which this care is transferred to the adult healthcare system is crucial to the continuing wellbeing of the young person and their willingness to continue and comply with health support and treatment.

In many instances, the young person and their family are well known to staff within children's health services. Relationships based on trust and, in many instances, friendship built over many years will have developed, making the transition to adult care all the more daunting, particularly if the child's condition has required frequent intervention from the health service or if the young person's condition is rarely seen in adult services.

Health professionals from both children's and adult health services are well placed to help the young person and their family prepare for the eventual transfer to adult care.

It is important that transition is seen as a process and not an event, and preparation should start early. Often the first to be involved with a baby or young child with special needs, health professionals can help ensure that choice, self-management and independence are already familiar concepts to families by the time they become teenagers. However, to be really successful it is important that GPs and adult services are closely engaged too in preparing the young person for the eventual transfer to their care.

I welcome this document setting out the needs of these young people at such an important and influential time for their future health and wellbeing.

Sheila Shribman
National Clinical Director for Children

This good practice guide to transition planning will be a useful tool not only for physicians but all health professionals and their partners in both children's and adult health services in preparing young people for greater independence and for the time when they leave children's services.

Although the transition to adult services has historically been regarded as a matter for children's services, this is no longer the case. Children are surviving longer into adulthood with conditions that once they would have died from and it is important for adult services to be engaged much earlier in the planning of the transfer of care, at an appropriate time, so that the young person and the service are properly prepared. This guide provides useful information on how that can be achieved. I am delighted to support its publication.

Dr Chris Clough

Medical Director, Joint Royal Colleges of Physicians Training Board

Medical Adviser, External Reference Group, National Service Framework for Long-term Neurological Conditions

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Introduction

More children with complex health needs now live into adult life yet health services have not always recognised the need to prepare them for the move into adult services. *Transition: getting it right for young people*, published by the Department of Health and Department for Education and Skills in 2006, highlighted that all young people with health needs are at risk during transition and that those with neurological disorders and disabilities are the least well served. GPs and adult services must recognise their long-term health needs so as to deliver appropriate services. Health needs include therapeutic and practical inputs, treatment for complications and functional deterioration which may result from progressive conditions, appropriate treatment for everyday and unrelated diseases, and understanding about what young people can do to maintain their own health.

For all young people, the transition from childhood to adulthood involves consolidating identity, achieving independence, establishing adult relationships and finding meaningful occupation. For young people who are sick or disabled, this transition is made more difficult by concerns about whether, how and where their health and social care needs will be met. Many young people feel vague about the transition process because they have not been given the opportunity to discuss it, and families report that they are faced with a 'cliff edge' where services fall away when the young person reaches the age of 16. Satisfaction with many aspects of transition from children's to adult services and future engagement with the health service can be improved through implementation of a structured, coordinated health transition plan.

Transition services therefore need to support young people with a range of conditions, varying from those who will attain independence despite having a long-term condition, to those who have a progressive life-limiting disease. Some who have non-progressive long-term conditions will nonetheless be at risk of functional deterioration with increasing age.

The process of transition should start while the child is being cared for by children's services and may, subject to the needs of the young person, continue for a number of years after the transfer to adult services. Thus, for young people with complex continuing health needs and/or a disability, successful transition from childhood to adulthood demands not only the engagement of the young person and their family, but also both children's and adult health services and the GP.

Crucial to the successful transition of all young people is forward planning based on the needs of the young person and their family, thus instilling confidence in both that their unique needs will be recognised and addressed. Ensuring that children and parents know about the opportunities and choices available and the range of support they may need to access is something which cannot start too early.

While relevant to all health needs, this good practice guide has a particular focus for young people with disabilities which include conditions such as cerebral palsy, muscular dystrophy and spina bifida, as well as learning difficulties (developmental coordination disorders), learning disabilities, sensory impairments, autism spectrum disorders, acquired brain injury or intractable long-term conditions/syndromes (such as some forms of epilepsy).

This guide builds on a wealth of good practice and aims to:

- place the young person's needs and aspirations at the centre of the transition process;
- reinforce the need for a clear inter-agency planning structure which is based on good communication, education and training of staff, has agreed protocols that take account of national standards and evaluates outcomes of local planning to improve experiences of transition for these young people;
- acknowledge that transition does not end when the young person moves on from child-centred services but continues in adult services;
- highlight practical approaches through which both the children's and adult health services can contribute to improving the transition process for young people with complex needs (including mental health, long-term conditions and palliative care) and disabilities (both those with and without statements of special educational needs (SEN)); and
- support the commissioning process by clarifying the driving principles of person-centred planning and partnership working, clarifying the roles and responsibilities of the professionals/main agencies involved in the transition process.

It supports *A transition guide for all services: key information for professionals about the transition process for disabled children*, which was published by the Department for Children, Schools and Families and the Department of Health in October 2007.

The Government is initiating and developing a Transition Support Programme¹ which will be rolled out across the country. This good practice guide for health professionals will therefore be reviewed to take into account any new arrangements that arise from the national programme.

¹ HM Treasury/Department for Education and Skills (2007) *Aiming high for disabled children: better support for families*. London: HMT/DfES.

Vision

'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.'

National Service Framework for Children, Young People and Maternity Services (2004), Standard 4.

Planning for transition

Reasons for developing a health transition plan

Evidence of the benefits of **planned transition** is now emerging² and a good transition can improve health-related quality of life for young people with complex health needs and disabilities.

Young people and those working with them often have low expectations and there is insufficient flexibility to enable access to further and higher education or employment. Pathways such as the Association for Children's Palliative Care (ACT) Transition Care Pathway set out a care pathway approach to transition, identifying key points and standards for young people with palliative care needs. The pathway offers guidance on planning transition during instability and, if required, providing end-of-stage care for young people during a transition process.

A distinction needs to be made between the physical transfer to adult services and the process of transition from childhood to adulthood. Well-planned transition, sensitive to underlying needs, improves health, educational and social outcomes for young people. Good planning that puts the young person at the centre will prepare them and their family for the move to adulthood and transfer to adult healthcare, and early engagement with adult health services and continuing links with the GP reduces the risk of overdependence as young people and families move on from comprehensive children's services.

2 Association for Children's Palliative Care (2007) *The Transition Care Pathway: a framework for the development of integrated multi-agency care pathways for young people with life-threatening and life-limiting conditions*. Bristol: ACT.

T is a young woman in her mid 20s who has Friedreich's ataxia.

Reviewing how her transition went for her, she singled out critical factors that can make it successful. These include:

- being treated as an individual;
- good inter-agency information and liaison;
- key worker support but not dependency;
- developing her own advocacy skills;
- coordinated appointments that minimise interruption to education;
- opportunities and support for independent living; and
- flexible training and employment schemes.

A poor transition out of children's services with lack of continuity and follow-up may lead to a disengagement with health services and can have serious outcomes for young people as well as incurring additional health service costs.³

During the transition process, various plans will be made in relation to different aspects of the young person's life – further/higher education, vocation and training, leisure and independence, where they wish to live and ongoing healthcare. Health professionals working with a young person with complex health needs or a disability can prepare them for adulthood by developing a health transition plan, which takes an approach that is much broader than the medical diagnosis and helps the young person to address other lifestyle issues that may be concerning them. This needs to

3 Watson AR (2000) Non-compliance and transfer from paediatric to adult transplant unit. *Pediatr Nephrol* 14: 469–72.

form an integral part of the broader transition plan, linking closely with education and social care.

Disability should be seen from a social perspective which identifies the impact of health needs and promotes participation, activity and quality of life.⁴ Young people want others to see them firstly as young people and not as 'disabled'.⁵ For example, in one epilepsy clinic, teenagers' main concerns were employment, driving and sexual health. Health professionals working with a young person to develop a health transition plan need to take a broad and flexible approach.

Developing a health transition plan (health plan)

The planning process needs the involvement of an integrated multidisciplinary team of people (including the GP) who have the appropriate training, expertise and skills and who are able to cross-refer to provide coordinated care. Successful planning is person centred and recognises that the young person's needs will change over time. It may be a simple or complex process depending on the young person's condition and the range of services required.

The health plan needs to be developed by the young person, supported by the most relevant health professional/transition key worker or other relevant multidisciplinary team member who can review it regularly with them. The professional developing the transition plan has a role in helping the young person navigate their way around the health and social care system. The health plan should be initiated at the start of the transition planning process. In line with transition planning in schools, this means starting by 13 years old at the latest. However, the plan should be a continuous process and can be developed further at any stage, including following transfer to adult services when it may be referred to as a care plan.

A health plan comprises a self-assessment by the young person to identify their day-to-day needs and, in discussion with health professionals, an action plan to meet these needs in preparation for moving into adult healthcare provision.

4 World Health Organization (2001) *International Classification of Functioning, Disability and Health*. Geneva: WHO.

5 Watson N, Shakespeare T, Cunningham-Burley S and Barnes C (2000) *Life as a Disabled Child: a qualitative study of young people's experiences and perspectives*. Edinburgh: Department of Nursing Studies, University of Edinburgh.

It is a personal plan that describes what a young person can do to be healthy, to reduce the impact of health needs on future choices and maximise opportunities for independence. It should be offered to all young people but not all will wish to have one. Some young people will be confident enough to complete this independently, while others may need help in preparing it, particularly those whose disability makes it difficult to complete the assessment form themselves, who have limited understanding or whose first language is not English. Some young people may prefer help in completing it from outside their family/carer and an independent advocate may be able to assist.

An example of a transition planning tool is given in Annex B. There are other templates available at www.transitionpathway.co.uk, which may be useful for young people with cognitive impairment or other difficulties.

A health plan should:

- help the young person to become more knowledgeable, confident and competent in understanding and (with support as necessary) making decisions about managing their own health needs (or informing others who can provide assistance);
- help the young person – as well as families, carers and professionals – to be fully aware of the opportunities for minimising the impact of health needs on their future choices and of the interventions and strategies that can widen opportunities;
- provide a recognised process for clarifying current and future health needs and sharing information where appropriate, with both paediatric and adult services in relevant agencies, informing both clinical and strategic planning; and
- ensure that health needs/management are identified within a broader transition plan and that the young person is supported in a way that takes account of needs in all areas, leading to a plan which is clear, comprehensive and avoids duplication.

The key principles of health transition planning

1. Planning is person centred and needs focused, identifying the hopes, aspirations and goals of the young person who plays an active part in decisions about their future.
2. It assesses the likely impact of future health needs and identifies interventions/strategies.
3. It sees transition as a process and develops flexibility in moving to adult services depending on a young person's wishes, needs and developmental readiness.
4. It explores, with young people, opportunities for independent living and developing skills in monitoring/managing their conditions and in developing and improving their self image.
5. It helps a young person understand how to access adult services and fully engages children's and adult health services in planning for an individual young person.
6. It develops a health plan with the young person, and their family and carers, identifying the most appropriate health professional to coordinate this.
7. It takes account of physical, psychological, social, educational and vocational dimensions and the need for equipment/adaptations.
8. It observes local information-sharing protocols, taking account of a young person's wishes for confidentiality.
9. It ensures a good working knowledge of the professional roles of the core health transition team as well as those in other agencies.

The key principles of health transition planning (*continued*)

10. It works closely with other agencies to ensure that the health plan is shared, when appropriate, and incorporated into a young person's broader transition plan (through the statutory review process for those with SEN statements but also for other young people).
11. It continues to support the young person in their development of adult roles and responsibilities once they have transferred to adult services.
12. It engages both children's and adult health services in identifying areas of unmet need and planning at strategic level.
13. It develops services that reflect the need for a comprehensive transition health team, with specific roles as well as generic competencies.

What should a health plan cover?

The health plan will need to reflect the young person's views about their health needs, how they can be managed and whether they may influence future choices, and the young person's goals in the context of health needs.

The young person together with the relevant health professionals should identify strengths and needs in all key areas of their life – general health and wellbeing, aids and equipment, advocacy, social skills, vocational and educational needs should be identified, which may include:

- physical health and wellbeing, e.g. nutrition, vision and hearing, dental care and oral health;
- physical fitness and coordination, e.g. mobility and postural management;

- neurological health and wellbeing, e.g. perceptual skills, sensory responses;
- cognitive development and communication;
- medical management, including medication;
- personal care, e.g. personal hygiene, continence and sexual health, health promotion and risk management;
- emotional or mental health needs/psychosocial support, spiritual wellbeing and interpersonal/social skills;
- learning and pre-vocational skills (home activities, work experience, holiday jobs) and vocational needs (access to education, training and employment, workplace skills);
- independence needs, e.g. equipment, environmental adaptations and housing; and
- community participation/leisure, self-advocacy and independent living.

The practicalities of managing the process of moving to adult services should address:

- health support required, including opportunities for self-determination and training;
- advocacy and peer support;
- links with other agencies; and
- information sources (in addition to any local young person's information pack, which will cover education, training and work options) including support groups and websites such as www.youthhealthtalk.org (for young people with chronic or long-term medical conditions) and www.transitioninfonet.org.uk.

Young people may also need help in understanding the implications of their condition for sexual and reproductive health and some may want genetic advice and counselling.

For some young people, a key worker and a key worker designate (in adult services) will play an important role in supporting this process.

Parents and carers may also need support as the young person takes on more independence and new challenges.

A suggested health plan summary is given in Annex B. A Word version of the template is available at www.dh.gov.uk/en/Policyandguidance/Healthandsocialcaretopics/ChildrenServices/Transitionfromchildrenstoadulthealthservices/index.htm

Engaging the young person

Young people and their parents or carers may vary in their approach to following prescribed treatment or management plans and the challenge to healthcare providers is advocating for the young person while, at the same time, including parents or carers.

Started in good time, transition planning should be an evolving process in which a young person is gradually encouraged to take increasing responsibility and parents are able to adapt to changing needs.

Consistent liaison with the multi-agency team is particularly important to ensure that 'looked-after' children and young people in the care of the local authority are able to access health support.

The planning process needs to be based upon the young person's views about their health needs and how they may affect future choices, helping to identify the young person's goals and describe how the practicalities of transferring to adult services will be managed. It is likely to include:

- assessment of immediate medical needs and potential future needs, including risk assessment;
- identification of support needed to assist self-determination, maintain/develop opportunities for independent living, delay deterioration in physical or mental health and promote social inclusion;
- review of treatment plans;
- involvement of services and support to enable young people to play a full, inclusive role in society, including housing, transport, benefits, education, careers advice, employment, leisure and voluntary sector agency support;
- review of information provision, including its timing and level of detail to ensure that it is useful and appropriate;
- consideration of health promotion issues such as sexual health, weight management and smoking cessation and provision of access to a full range of health promotion services;
- taking account of identified coincident health issues; and
- consideration of any care and support provided (or needed by) family members/ carers and how this might change over time – does the young person wish to stay at home? Can the family continue to support the young person? Do they want to continue in this role?

It may be helpful to complete a healthcare skills checklist and update it regularly with the young person (see Annex B). This can help to inform the health plan and form the basis for a summary of transition needs. A Word version of the healthcare skills checklist is available at www.dh.gov.uk/en/Policyandguidance/Healthandsocialcaretopics/ChildrenServices/Transitionfromchildrenstoadulthealthservices/index.htm

Who should coordinate the health plan?

Young people and families particularly value having one main person who can help guide them through the complex transition process.

With the agreement of the young person, the transition key worker (key worker) and/or professional in the child health team who has most ongoing involvement with the young person and family and/or the key worker designate in adult services is best placed to fulfil this coordination role and work with the young person. It can be helpful to take the lead in reviewing health needs with the young person, involving other members of the team as required at the same outpatient appointment.

The key worker must be knowledgeable in working with young people and familiar with relevant adult as well as children's services and the difference in culture between these two systems.

It is also important to recognise that some young people may be transferring to a new geographical location, e.g. to attend college or university, training or employment; therefore, knowledge of how to find out about and make links to services in these new areas is also important.

What does coordination involve?

The key worker should discuss with the young person whether they wish to have a plan and how this might be organised.

If the young person has limited mental capacity, they may need supporting in order to ensure that they are properly engaged.

The key worker/key worker designate will need to identify with the young person and family which core health professionals are/should be involved. This may include hospital and school doctors, GP and practice nurses, school nurse, occupational therapist, physiotherapist, speech and language therapist, specialist and community children's nurse, district nurse, learning disability practice nurse, community matron, psychiatrist, clinical psychologist, endocrinologist for patients with delayed development or rheumatologist for patients with muscular dystrophy. It could also include long-term respiratory support and/or a cardiologist and palliative care specialist. Where the young person has a life-limiting condition requiring increasing assistance to maintain quality of life or manage at home, the health plan might be coordinated by a therapist or community nurse. Normally, a nurse in a palliative care team or, in children's or adult hospices, a district nurse, community matron or Macmillan nurses are key resources.

Professionals in both children's and adult health services must be included and the key worker/key worker designate should, with the young person and if appropriate their family, meet with the new adult specialist, perhaps at the time of the outpatient appointment or at other times (with the patient's/carer's permission).

As the person responsible for the young person's ongoing medical care, the GP may become the key worker designate or be a key member of the adult care team. At a minimum they should be kept fully informed and involved throughout the child's/young person's care, thus ensuring that they are fully informed about plans for their care prior to and during transition.

Health professionals taking the coordinating role should always work in partnership with young people, enabling them to increasingly take on coordination of their own health plan as they move into adult services.

As a trusted adult, the professional's role may include challenging and supporting young people, acting as their advocate and helping them to develop their self-advocacy skills. For example, when formulating a health plan, a young person may be hesitant in identifying some areas of need so, where a young person does not do so, the key worker should aim to ensure that the young person has understood the questions and made a realistic self-assessment. Tools such as person-centred planning can engage young people in planning their transition.

Where the young person has a specific additional medical need – e.g. diabetes, renal disease – the health plan should be completed with the young person by the relevant doctors/specialist nurses and team. Where the young person has a complex or long-term condition – e.g. cerebral palsy, muscular dystrophy, acquired disability or autism spectrum disorder – the health plan might be better coordinated by the paediatrician, nurse, physiotherapist or occupational therapist.

The health plan should be recorded and it should include action points (which may include referral to other services), who is responsible for carrying them out and when the plan will be reviewed.

Where a need is identified but no service is available, this should be recorded and notified to commissioners. The young person and their family may also wish to make a response and should be advised of procedures to make a complaint.

With the young person's consent, ensure that information is copied to relevant professionals/agencies (children's and adult services) and shared at statutory transition reviews (for children with SEN statements) or other review meetings. Where other health professionals are providing a significant input, health plan information should also be shared with them.

The key worker should consider how to develop the young person's ability to share the information as they move through the process, e.g. does the young person want to receive copies of letters themselves and which professionals do they want to share the information with? This should be kept under review.

Health plans should also take continuous account of policies for child protection and protecting vulnerable adults and of the statutory equality duties for public bodies.

Key working in a multi-agency context

Where there are significant health needs, the lead professional may be the most appropriate person to take on the more general role of **key worker**. This case worker

approach is particularly relevant where there are complex needs with multi-agency involvement.⁶ Where health needs are less significant, it is still important for the key worker to liaise with the key worker in another agency. A key worker designate within the adult service who can gradually take over the role will also help ensure a smooth transition.

Key working (in children's or adult services) involves regular, active contact with the young person and their family, offering support, information and advice, coordinating effective and timely service delivery, and acting as an advocate.⁷ Clinic visits or other appointments offer an opportunity to develop plans, avoiding inconvenience to the young person and making best use of existing resources.

Timing

Transition planning should begin at the latest by the age of 13/14 (Year 9 in school) although parents may wish to raise concerns before this and children can be involved in the gradual development of independence from the age of about 6/7. The health plan will evolve over time as the young person explores preferences and opportunities and will need to be reviewed at regular intervals.

Who holds the health plan?

The young person (and their family) and the coordinator, with copies for involved professionals, including the GP.

6 While A, Forbes A, Ullman R et al. (2004) Good practices that address continuity during transition from child to adult care: synthesis of the evidence. *Child: Care, Health and Development* 30(5): 439–52.

7 Barton L and Clarke L (2005) *Altogether Now: An evaluation of the keyworking processes in Warwickshire*. Warwick: Warwickshire County Council.

Multi-agency working

A number of models for health transition exist, and it is clear that different models are effective in different settings and conditions. Models include the transfer from paediatric sub-specialist to adult sub-specialist; a primary-care-based model coordinated by the GP; the development of generic adolescent health services; and the development of a community-based young adult team, which might be coordinated by a consultant in rehabilitation medicine. Whichever model is used, a key feature is the presence of a skilled multidisciplinary team able to take responsibility for both long-term health needs and disability management. Other models include learning disability teams, community matrons and district nursing teams.

Effective joint working is based on a clear understanding of professional roles and efficient communication systems. The importance of multi-agency working underpins all sections of this guidance. Within the multi-agency team, a key worker and key worker designate needs to be identified for each individual young person.

Roles of core professionals in transition

The overall transition plan requires multidisciplinary and multi-agency input. It is critical that everyone understands the roles of different professionals and how to access services, so as to ensure that young people get the right support and duplication is avoided. In addition to their specialist input, any of the health professionals involved could also undertake the role of health plan coordinator, depending on the wishes of the young person and their most significant area of need. However, all practitioners should take responsibility for referring on to appropriate services linked to their specialty.

It is important that adult teams have the skills to manage the later stages of transition and the long-term health needs of adults with complex long-term conditions in a coordinated manner.

Throughout the transition process, all agencies have a responsibility to work together. Health professionals, school staff, the Connexions personal adviser and the transition social worker need to work in partnership with the young person and family to agree how they prepare for the process of transition and how the young person will be supported to have a lead voice in planning and reviews. Health

services should support the vocational and employment needs of young people beyond traditional health settings. A review of the outcomes for 16 to 18-year-olds with learning difficulties and disabilities in college⁸ identified the need for better multi-agency working to help college staff understand complex needs and support young people more effectively. Non-statutory and voluntary agencies should also be involved as appropriate.

Information sharing and confidentiality

From the start of the process, professionals must work with the young person and their family to ensure that, with their permission, information is shared to inform each other's assessments and coherent planning is based on a real understanding of the young person's needs. Where the young person does not have the mental capacity to make these decisions, the provisions of the Mental Capacity Act 2005 should be taken into account. Whenever possible, a joint assessment should be carried out.

The transition process should be facilitated by inter-agency sharing agreements to which the local authority, Connexions, primary care trust (PCT) and other health trusts are signatories.

The specific responsibilities of each agency contribute to the comprehensive support a young person requires.

⁸ Ofsted (2007) *Current provision and outcomes for 16- to 18-year-old learners with learning difficulties and disabilities in colleges*. London: Ofsted.

Responsibilities of health professionals working with young people

Engagement with transition planning through:

- team working within health services and across agencies;
- specialist input as required;
- planning with the young person and their family to ensure timely referral to adult health services and a gradual process of transition;
- agreement as to the most appropriate person to coordinate a health plan and how the summary will be shared with other agencies, specifically with the Connexions personal adviser and other coordinators (e.g. the headteacher);
- written reports and attendance at school annual reviews for young people with statements of SEN;
- attendance at transition planning meeting(s) for young people without statements. Where there is a significant health condition, health professionals may need to initiate such a meeting (a similar system of annual review may be helpful);
- knowledge of other agency referral systems and eligibility criteria;
- review of the transition process and outcomes for young people;
- clarification of unmet needs and informing commissioners;
- identifying and sharing good practice;
- accessing and providing training; and
- health representation on local transition strategy groups.

For a summary of the professional roles of the core transition team, see Annex A.

Planning and commissioning for better health transition services

With more young people with complex needs surviving well into adulthood, adolescence provides the opportunity to promote the most effective use of health services, focusing on health promotion, informed risk awareness and self-management.

At age 16, young people with disabilities have aspirational levels similar to their non-disabled peers, yet these diverge significantly in early adulthood.⁹ The consequences of a poor transition out of children's services with lack of continuity and follow-up can have a serious impact for young people as well as additional health service costs.

Many young people feel vague about the transition process because they have not been given the opportunity to prepare for this stage in their development. However, satisfaction with many aspects of transition from children's to adult services can be improved through the implementation of a structured, coordinated programme of transitional care.

Part of the challenge to providers is to adapt ways of working that provide better, more integrated support for young people. However, service redesign needs to be underpinned by effective commissioning of transition health services. Central to this is joint planning based on a shared understanding of local needs. Health professionals, managers and commissioners need to work together to design, commission and implement accessible and effective services to assure young people and families of the provision of coordinated, uninterrupted healthcare.

The following suggestions therefore draw on a range of developing practice and are offered with the intention of encouraging debate and the trialling of practical applications to help meet young people's needs more effectively.

To be fully effective, a transitional care programme should aim to achieve:

- a high-quality, safe and effective service responsive to the local transition needs of both children and young adults;

⁹ Burchardt T (2005) *The education and employment of disabled young people: Frustrated ambition*. York: Joseph Rowntree Foundation, Policy Press.

- reduced risk of poor health outcomes and health inequalities through the provision of clear information from PCTs to families about how to access healthcare and support for young people with disabilities and complex needs in the local area. As part of the 'core offer' for disabled children, this should include information about children's and adult health services;
- better long-term health and wellbeing, access to education/employment and improved social inclusion;
- effective liaison between children's and adult health services; and
- acute and community clinicians playing a prominent role in guiding young people and families through the transition process.

Planning the service

By 2008, local authorities are required to have in place a children's trust model that delivers integrated working at all levels. The duty of partnership includes SHAs and PCTs. While children's services are usually organised within a multidisciplinary framework, fewer adult services currently work in this way; the aim should be a seamless transition pathway, which addresses relevant factors, including cultural differences. Frequently, a young person's aspirations are undermined by deficiencies in therapy programmes, equipment and housing adaptations, with adult physiotherapy and occupational therapy especially under-provided.¹⁰ Adults with complex, physical disabilities are a high-needs health group requiring frequent inputs,¹¹ yet young people and their families have frequently told us that the quality of healthcare declines significantly after transfer.

Transition health services should take account of all young people with complex needs and review how services, including child and adolescent/adult mental health and learning disability services, can work in partnership with services for young people with physical disabilities, and determine whether there are opportunities

10 Ko B and McEnery G (2004) The needs of physically disabled young people during transition to adult services. *Child: Care, Health and Development* 30(4): 317–23.

11 Young N, Steele C, Fehlings D et al. (2005) Use of health care among adults with chronic and complex physical disabilities of childhood. *Disability and Rehabilitation* 27(23): 1455–60.

to enhance effectiveness and avoid duplication. Access criteria in different services should be sufficiently flexible to ensure that the young person receives the most appropriate support.

Clear lines of responsibility and team approaches for supporting young disabled adults need to be established. As well as responding to unmet needs, commissioners should review and, where appropriate, redesign existing services to meet the complex health needs of young adults more effectively. Multidisciplinary working is emphasised in the *National Service Framework for Long-term Conditions*, published by the Department of Health in 2005; it underlines the importance of maintaining independence and social and psychological wellbeing, including personal care, equipment, (assistive technology) and housing planned around individual needs. Young people currently face unacceptably long waits for assessment and provision of wheelchairs and other equipment, which can make a big difference to dignity and independence. These need to be addressed and, where there is already shared agency responsibility for services such as integrated community equipment, responsive joint planning is required.

To meet individual needs more responsively, flexibility of funding and provision is vital so that a young person can move into adult services at the appropriate time – effectively adopting a lifespan approach.

Characteristics of good transition services

- An agreed process for joint strategic planning between children's and adult health services.
- A clear transition care pathway.
- Clear identification of the key worker and key worker designate.
- A focus on person-centred planning.
- Excellent links across adult and children's services.
- A multi-agency model.
- A service responsive to the needs of young people and their families.
- Reduced risk of poor health outcomes.
- A reduction in health inequalities.
- Better long-term health and wellbeing, access to education/employment and improved social inclusion.
- Effective health contribution to strategic planning for transition service.
- Improved follow-up.
- Flexible, timely response: early intervention and prevention through individual health plans, avoiding hospital admission, where possible.

Characteristics of good transition services (continued)

- Integrated multi-agency health transition plans and pathways which enhance a young person's ability to take appropriate responsibility for managing their own health needs, promoting choice and opportunities for independent living. Plans must take into account the young person's transition from school to college, training or employment.
- The opportunity to develop self-management and self-referral, as appropriate.
- Risk management procedures including effective follow-up for vulnerable young adults.
- Young people (and their families on their behalf) using primary care appropriately.
- Transition teams with core professionals who deliver a comprehensive service.
- A skill mix which ensures that adolescent health expertise, professional/clinical leadership, key working (where required) and supervision of support staff are available.
- A joint planning and funding process within the PCT/primary care/local authority for multiple, ongoing needs.
- Specialist commissioning for needs, such as palliative care or rarer conditions, where evidence demonstrates the benefits of regional partnerships or more centralised tertiary services in conjunction with managed health networks.
- Identified quality standards to enable performance management.
- Measurable outcomes to ensure a value-for-money service.

Commissioning

The *Commissioning framework for health and well-being*, published by the Department of Health in 2007, has a strong focus on addressing inequalities in access to health services and advocates increased co-location of appropriate services. The framework has been developed to ensure that commissioners are fully equipped to commission services in the most effective way, for the best outcomes. This means understanding the local community, having clear and accurate data, involving service users and key partners such as the voluntary sector, and creating a transparent procurement process. It also recommends setting and agreeing clear standards of service provision expected of service providers and by which they can be performance managed.

Effective transition services for young people who will continue to need healthcare provided by the adult healthcare sector for long-term conditions require a range of flexible, sensitive services to be developed, taking account of the physical, psychological, emotional and practical needs of the young person as they approach adulthood and beyond. Key factors that will assist the development and commissioning of effective transition processes are:

- a 'whole-systems' approach, identifying and involving key players from the start, including adult health services, primary care and other agencies;
- appointment of a health transition lead (a local 'transition champion') to promote and coordinate transition developments across care groups and between children's and adult services, and identify this responsibility in their job description and/or job plan;
- collaborative working between commissioners and providers responsible for commissioning children's and adult services in PCTs, acute health trusts and other agencies;

- knowledge of the number of young people who will require transitional support and the nature of their health needs including those in out-of-area placements, 'looked-after' children and those without statements of SEN. This knowledge needs to be linked to local authorities' data collection to enable the sharing of basic information while protecting individual confidentiality, through the Integrated Children's System supported by the Common Assessment Framework (see www.everychildmatters.gov.uk/socialcare/ics and www.everychildmatters.gov.uk/deliveringservices/caf/);
- agreed categories of need, based on collected data, taking account of user views, for example through young people/parent forums and professional consultation;
- reviewing existing provision against the needs of young people;
- identifying current strengths and weaknesses;
- developing a pathway especially for young adults in partnership with clinicians in child and adult health services across the range of specialties and services;
- planning and developing provision for young people;
- identifying resources and setting priorities;
- clarifying outcome indicators, taking account of particular groups of young people, in consultation with front-line staff in children's and adult services;
- analysing the current workforce in children's and adult services and challenging established patterns of provision, informed by the skill set needed to deliver agreed outcomes;
- identifying resource allocation (time commitment) for health professionals to take on health plan lead professional and key worker roles;

- preparing for adult services to meet a range of need, from provision in mainstream acute or community settings to complex continuing care (in partnership with local authorities);
- consulting with key partners – local authority, schools, the Learning and Skills Council, lead council members and non-statutory organisations – making use of joint commissioning, pooled budgets or direct payments to fund services and increase user choice;
- improving accuracy of tariffs for existing and planned services; and
- monitoring and reviewing services and outcomes on a regular basis.

For further information, see the *Children and Young People's Plan* (www.everychildmatters.gov.uk/strategy/planningandcommissioning) and the *Commissioning framework for health and well-being* (www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_072604).

Mechanisms for delivery

The aim is for health professionals in acute and community services to facilitate a planned transition process between children's and adult health services with effective communication systems for liaison on individual needs. Good liaison between specialist or tertiary services and local primary/secondary care is essential.

The team approach

While a few specialist centres have adolescent medicine departments, many services will need to consider other ways of providing cost-effective, local support in acute and community settings. The multidisciplinary/multi-agency transition team is considered to be an effective model, costing no more than an ad hoc service but more likely to enhance participation in society.¹²

Young people need dedicated health and social care teams.¹³

12 Bent N, Tennant A, Swift T et al. (2002) Team approach versus ad hoc services for young people with physical disabilities: a retrospective cohort study. *The Lancet* 360: 1280–6.

13 While A, Forbes A, Ullman R et al. (2004) Good practices that address continuity during transition from child to adult care: synthesis of the evidence. *Child: Care, Health and Development* 30(5): 439–52.

At present, there is rarely an equivalent to coordinated paediatric care within adult services; therefore, adult and children's services need to work within both children's and adult services. Existing teams cover various age ranges; however, 13/14 to 25 years may be a useful (and developmentally appropriate) model.

Team responsibilities include:

- identifying young people with transition needs;
- providing a service to young people with complex needs, taking on lead professional/key worker roles where appropriate;
- providing advice and support to young people and families; and
- sharing knowledge and expertise with those who work less frequently with young people.

Each element of the transition pathway needs to be assigned to the most appropriate team member.

See Annex A for the roles of the core team.

Education and training

Health professionals working with young people should have access to specific adolescent training programmes in addition to local, multi-agency training. Evidence suggests that the unmet training needs of doctors and other health professionals are similar, supporting the development of multidisciplinary training.¹⁴ A study examining multidisciplinary training needs in adolescent health within a large paediatric hospital in the UK identified lack of formal training as a major barrier to providing quality care for young people.

¹⁴ McDonagh JE, Southwood TR, Shaw KL and British Paediatric Rheumatology Group (2004) Unmet education and training needs of rheumatology health professionals in adolescent health and transitional care. *Rheumatology (Oxford)* 43(6): 737–43.

In conjunction with a range of stakeholders and the Department of Health, the Royal College of Paediatrics and Child Health is now developing a multidisciplinary, interactive, e-learning adolescent health curriculum including modules in long-term conditions and/or disability and transition. This programme is intended to provide a range of resources through web-based and other media which can be accessed by health professionals working with young people, and can be incorporated into continuing professional development and learning portfolios, contributing to improved service quality for young people.¹⁵

Health involvement in multi-agency transition planning

It is essential that health professionals and commissioners play a full role as partners in multi-agency planning and review, in the context of both children's trust and adult service planning arrangements. This can be done through processes such as children's and young people's plans and formal inspection procedures, including joint strategic needs assessments and local area agreement provider frameworks for planning and evaluating transition services.

A positive model is a local multi-agency strategic transition planning group linked to the Children's and Young People's Strategic Partnership Board (which includes PCT representation). Sharing information with the Learning Disability Partnership Board helps to inform planning for adults with learning disabilities, but processes are also required to provide information to adult services for young people with other needs or disabilities. Links need to be made with primary care, acute trusts and mental health services.

Multi-agency strategic planning groups should be responsible for overseeing the work of locality groups that review transition outcomes for individual young people.

Most local authorities are producing transition guidance and it is essential that health staff contribute information about local health services and procedures for multi-agency working.

¹⁵ www.rcpch.ac.uk/Education/Adolescent-Health-Project. Other training material is available at: www.youthhealthtalk.org; www.euteach.com, a European initiative to provide web-based teaching resources for adolescent health; and www.tsa.uk.com, the Trust for the Study of Adolescence.

In addition to guidance on government websites (www.dh.gov.uk; www.dh.gov.uk), the Transition Information Network (www.transitioninfonetwork.org.uk) is a useful resource of information and good practice for young people, families and professionals.

Review

Monitoring and evaluation of health transition provision needs to recognise what is important to people using the service.

Young people value:

- continuity (for example, of health staff so histories do not need to be repeated);
- changes that are less stressful and don't occur at the last minute;
- maintaining previous links and relationships; and
- making decisions in the context of friendships and peer experiences.

Parents value:

- information on options and processes;
- planning in good time leading to reliable arrangements;
- more transparency about funding; and
- good all-round life experiences for the young person (independence, confidence, activities and friendships).

Performance management

- Review health planning process and access to relevant services.
- Track outcomes for individual young people via health plans.

- Audit service quality and provision within a multi-agency context, using both quantitative and qualitative measures (see the service audit tool at Annex C).
- Analyse waiting times and gaps in service in relation to needs assessment.
- Evaluate feedback from service users, practitioners and (multi-agency) transition teams.
- Identify successful and innovative practice.
- Plan and commission service developments in light of identified needs, the evidence base, good practice and professional guidance.

Outcome measures might include 'clinical outcomes improved/maintained', 'young person/family satisfied with care' or 'young person able to access adult services successfully', as well as measures of personal development. The mechanism for collating information about outcomes/service requirements and reporting to commissioners needs to be clearly specified. This should lead to more focused commissioning (rather than block contracts).

Sharing information

Sharing of information between the young person and health professionals involved in their care and treatment is critical to successful transition. Through sharing information, the young person will become more knowledgeable about their condition and their future care can be managed in an open, transparent relationship in which they develop control and are able to make choices regarding their future.

Information shared with and between health professionals enables a consistent approach to the young person's care and treatment, which will contribute to much greater compliance with treatment regimes. Sharing information will also enable the clinicians, particularly those working in adult healthcare, to develop a greater knowledge and understanding of what has previously been regarded as paediatric healthcare. There is an opinion that at transition a clean slate is achieved, i.e. issues long since resolved are not handed over.

Strategies for young people and their families

Providing information packs relating to the specific condition, including contacts for local/national support groups and sources of advice, can be helpful to support health plan discussions. It is also useful to give out the local multi-agency transition guide for young people/parents.

Provide opportunities in a suitable environment for young people with similar needs – especially those in mainstream schools – to share experiences and work on solving some of the problems they face. Workshops supported by health staff for young people with complex conditions, developed in conjunction with their school/college, to look at self-advocacy, disclosure and negotiating arrangements, e.g. role-playing interviews, can be extremely useful.

Using self-disclosure prompts can help the young person share condition-specific information with their college or prospective employer, enabling them to present their disability-related or medical information in a positive light, for example:

- the name of their condition;
- specific work-related effects and how they can be managed;
- tips learnt from school/previous work experience; and
- modifications required to working procedures, the environment, or sources of professional advice and financial support (for building adaptations or equipment).

Further information is available from the National Bureau for Students with Disabilities (www.skill.org.uk).

All preventive/health promotion care and advice for young people should be routinely available for those with long-term health conditions or disabilities.

The Expert Patients Programme¹⁶ can help adults with long-term health conditions develop confidence in taking control of their own health needs; the Supporting Parents Programme is also now available at: www.expertpatients.co.uk.

Strategies for professionals

Every clinic letter to GPs should include a transition summary – ‘Transition issues reviewed today were as follows...’ – or enclose a copy of the updated transition plan summary (see Annex B).

Use up-to-date communications technology to keep in touch with young people, e.g. a nurse could text a young person to remind them about medication.

The current health plan can form the basis of a multidisciplinary summary when passing on information to new (adult) health teams.

A portfolio of parent, paediatrician and therapy reports can be helpful when the young person moves into adult services, along with multi-agency reports as appropriate.¹⁷

16 Department of Health (2001) *The Expert Patient: A new approach to chronic disease management for the 21st century*. London: DH.

17 Tan MJ and Klimach VJ (2004) Portfolio of health advice for young people with disabilities transferring to adult care. *Child: Care, Health and Development* 30(3): 291–6.

Good practice examples to support planning and commissioning

- Joint health (PCT) and local authority commissioning posts for children and young adults with complex needs and disabilities.
- Flexible funding and contractual arrangements (across paediatric/young adult services) to meet individual needs.
- Development of multi-agency transition protocols.
- Transition workshops for young people in schools/post-16 colleges to encourage active planning and use of health resources.
- Health included in multi-agency guides to local transition resources for young people and families.
- Multi-agency protocol for risk management in complex team-working situations.
- Multi-agency transition teams which include core health professionals as a minimum.
- Health services set up specifically for young disabled adults (popular with users).
- Age-appropriate settings where young adults can receive their care from health professionals.
- Services built around a professional lead role; commissioning on these lines can develop transition services with working protocols for both specific assessment of individuals and a training component to support other staff.

Good practice examples to support planning and commissioning (*continued*)

- Practice-based commissioning across a local area (in conjunction with the PCT) for the young adult service (18–25+) with a focus on neuro-disability, to provide intensive assessment/support when change or deterioration occurs (GP, self or professional referral). This could be based in an acute or community setting; it requires therapy and medical input, psychology, nursing and other allied health professional support, strong links to the wheelchair service, Connexions (or equivalent), education/employment settings and local authority involvement (social work, occupational therapy – equipment and adaptations).
- Multidisciplinary team supporting young people with specific needs such as autism spectrum disorder. The team includes psychiatry, psychology, occupational therapy, speech and language therapy, and links with carers and voluntary organisations, as well as providing training for other workers.
- Health professional working jointly with the local authority to develop individual care packages for young people with health needs who meet continuing care criteria.

Good practice examples for delivering effective transition

- Shared adolescent clinics (13–18/25), run jointly with paediatric/adult service staff. The benefit of this approach is higher rates of adherence to appointments where young people meet the adult health team prior to transfer and a smoother transfer from children's to adult care.¹⁸
- Options for young people to be seen without their parents.
- Coordinated and flexible appointment times to minimise disruption to college or work schedules.
- Approaches that recognise barriers from the young person's point of view. For example, relationships with disabled and non-disabled peers are often the most important issue for young people.
- Honest explanation of a young person's condition and associated health needs with opportunities to question, debate and make informed decisions.
- Routine follow-up to encourage attendance if young people fail to attend a second appointment in adult services.
- Multidisciplinary clinics for young adults with long-term or life-limiting conditions (close links with palliative care support when required).
- Opportunities for young people to meet peers/adults with similar health conditions who have experience of successful employment/independent living (peer support highly valued).¹⁹
- Forum/networking meetings for parents/carers to explore transition resources, meet professionals, learn about services and share ideas.

18 Kipps S, Bahu T, Ong K et al. (2002) Current methods of transfer of young people with type 1 diabetes to adult services. *Diabetic Medicine* 19(8): 649–54.

19 Morris JR (2002) *Moving into adulthood: Young disabled people moving into adulthood*. York: Joseph Rowntree Foundation.

Good practice examples for delivering effective transition (*continued*)

- Life skills programmes (home, school and community assessments and skill-building groups) to develop age-appropriate skills, starting with children aged 7–12 years.²⁰
- Integrated health and local authority occupational therapy services so that young people experience seamless approaches in developing skills and independence with the equipment and adaptations they require.
- When planned hospital admission occurs (e.g. elective surgery), lead professional sends health plan summary to acute team, so that hospital stay and discharge can be managed in the context of a broader health plan.
- Where the medical condition is stable, clinic reviews are arranged as required (not necessarily six-monthly) and negotiated with the young person and team (which could include self-referral, parent/carer, health plan coordinator or other professional).
- Transition teams with expertise in managing sensory and functional needs focusing on complex conditions such as autism spectrum disorders (linking with paediatrics, mental health, learning disability and other adult specialties).
- Occupational therapist working with the young person and school team to assess work experience environments and advise employers about access, adaptations and equipment, leading to improved employment prospects for young people.²¹
- Where possible, access to GP for more routine needs, e.g. repeat prescriptions (saving a hospital visit if no change has occurred).

20 Gall C, Kingsnorth S and Healy H (2006) Growing up ready: A shared management approach. *Physical and Occupational Therapy in Pediatrics* 26(4): 47–62.

21 Shaw K, Hackett J, Southwood T and McDonagh J (2006) The prevocational and early employment needs of adolescents with juvenile idiopathic arthritis: the occupational therapy perspective. *British Journal of Occupational Therapy* 69(3): 497–504.

Annex A: The roles of core professionals in transition

The overall transition plan requires multidisciplinary and multi-agency input. It is critical that everyone understands the roles of different professionals, working as a team, and how to access services, so as to ensure that young people get the right support and duplication is avoided. Professionals need to be committed to supporting young people to have high self-expectations and promoting such approaches in all settings. They need to know the differences in service provision between children's and adult services in order to prepare young people and their families effectively.

Children's and adult health services

The transition process is relevant to both acute and community services and includes mental health and learning disability teams. As well as providing services, professionals should be involved alongside young people in informing strategic developments.

Coordinating the health plan

Health professionals should contribute their specific expertise to teams supporting young people in transition.

Depending on the wishes of the young person and their most significant area of need, any children's or adult health professional could also undertake the role of health plan lead professional or key worker (in addition to specialist input). This may sometimes involve taking a key-working role. However, all children's practitioners should take responsibility for identifying transition needs and referring on to appropriate adult services where available.

Core team

A wide range of professionals may be involved in supporting a young person at any one time but the following are more likely to be involved with young people with complex needs and disabilities.

General practitioner

This is the family doctor providing continuing medical care/psychological support for the young person and their family in the community. The GP:

- provides diagnosis and day-to-day care for urgent medical needs;
- refers to specialist health and other services as required; and
- maintains the medical link with the young person through the transition process into adulthood.

Paediatrician

This doctor specialises in the medical needs of children and young people, and is usually based in a child development centre, hospital or community setting. The paediatrician:

- provides diagnosis and medical care for young people with medical conditions, illnesses or disabilities;
- advises young people about the implications of medical conditions and how to manage their own needs, including health promotion; and
- supports parents/carers in managing a young person's medical needs.

Child and adolescent psychiatrist

Child psychiatrists mainly work in child and adolescent mental health services (CAMHS), outpatient clinics in hospitals, specialised inpatient units, child and family services, young people's services and outreach services (e.g. in schools, nurseries or day centres). They work as part of a multidisciplinary service that may include other child mental health professionals such as child psychologists, child psychotherapists, family therapists, children's psychiatric nurses and social workers.

Child psychiatrists deal with a wide range of mental health problems. Young people with long-term conditions are vulnerable to emotional, behavioural and psychiatric problems, and these can cause worry and distress to them and those who care for them. A large part of a child psychiatrist's work is to identify the problem, understand the causes and advise about what may help, using a range of therapeutic approaches, both psychological and pharmacological.

Adult medical specialist

Adult medical specialists usually work in teams which include therapists, nurses and other health professionals. The adult medical specialist:

- is usually based in hospital, or sometimes based in specialist or regional centres;
- may work with children or young people but more often specialise in adult care; and
- provides medical management for particular conditions, e.g. in neurology, rheumatology, orthopaedics, audiology, ophthalmology, diabetic or respiratory medicine.

Depending on the diagnosis and health problems the young person is experiencing, several specialties may be involved in a young person's care. For example, three different specialties may be relevant to long-term neurological conditions – neurology, rehabilitation medicine and palliative care.

When identifying the relevance of referral to particular adult specialties, the following areas may be helpful in identifying the most appropriate specialist for referral:

- assessment and diagnosis;
- control of disease progression and prevention of complications;
- symptom management;
- provision of therapy (includes spasticity management);
- support for functional needs and independence – provision of aids and equipment, e.g. wheelchairs, specialist seating, environmental control systems and communication aids;
- practical coordination of support services including the NHS, social services and voluntary services;

- psychological support (including spiritual support); and
- management of death and dying with aftercare and bereavement support for families.

All young people with complex health disabilities who are at risk of functional deterioration need to be referred to a named adult physician who will see people with long-term conditions and not discharge them. The clinician most likely to fulfil this role could be a rehabilitation medicine consultant.

Rehabilitation medicine physicians tend to work in district-based services, and have good links with community support services. They may visit patients in their own homes. They often run specialist services for more common disorders, particularly head injury and multiple sclerosis, but also sometimes for adults with cerebral palsy, and are interested in the prevention and management of long-term disability and increasing social participation. Thus, they will have an interest in supporting young adults to live independently and move into further education and work. Rehabilitation medicine physicians have expertise in ensuring the provision of coordinated, wide-ranging services including therapies, aids and equipment, and social and psychological support.

Neurologists often work in regional centres and so have expertise in the diagnosis of rare neurological conditions. They may run specialist (multidisciplinary) clinics in areas such as ataxia, hereditary neuropathies, muscular dystrophies, multiple sclerosis and movement disorders. Neurologists may also run specialist services for people who have seizures or spasticity.

Palliative care physicians have a particular role in the treatment of life-limiting conditions, and focus mainly on symptom management (especially pain) and, with the multidisciplinary team, on social, psychological and spiritual support and management of death and bereavement. Some young adults are vulnerable to intercurrent illness and they may benefit from referral to discuss end-of-life issues.

Specialist doctors

Specialist doctors are involved in different aspects of management, including assessment and diagnosis, symptom management, control of disease progression and prevention of complications.

Young adults with neuro-disabilities or complex needs may require support from:

- neurologists with expertise in the diagnosis of rarer neurological conditions – they may run specialist clinics for particular conditions, including epilepsy;
- rehabilitation medicine specialists; and
- palliative care physicians.

Nurse

Nurses assess, plan, implement and evaluate nursing care. They do this in collaboration with young people and their carers and with other members of the multiprofessional team. Nurses also manage and coordinate care, and often lead and manage teams of care providers. They have a role in promoting health, assisting people to achieve optimum health. Young people with complex health needs, continuing care needs or disabilities may require a combination of these skills. Nurses work in a wide range of settings, including hospitals, GP surgeries, schools, higher education settings, occupational health, the community, hospices and palliative care teams.

All nurse pre-registration training includes a one-year general nursing common foundation course introducing the philosophical and holistic concepts of nursing, health and society; the fundamentals of the biological sciences, psychology and sociology; and essential clinical nursing skills. Students then specialise for two years in one of the following fields: learning disability, children (which incorporates young people), mental health or adult nursing. Each of these specialties has very different skills and competencies.

Young people with acquired brain injury/complex neuro-disability may require a combination of these nursing skills and the key worker concept works well. Many learning disability services only commence when the young person reaches 18.

Ensuring an appropriate mix of nursing input post transition is key to successful transition pathways.

Allied health professionals

These include:

Clinical psychologist

Clinical psychologists work in community and acute settings, often based in CAMHS or adult mental health services. The clinical psychologist:

- provides psychological assessment which may also assist diagnosis, including psychometric testing; and
- helps young people through the use of specific techniques, which may include pain or anxiety management, improving social communication, behavioural strategies or environmental modification.

Occupational therapist

Occupational therapists are based in health services (including CAMHS and adult mental health services) and local authorities. The occupational therapist:

- assesses needs to enable young people to develop maximum independence/ wellbeing and access physical, social and learning environments (in school/ college, employment or at home);
- maintains and develops coordination and fine motor skills, including hand function, for practical tasks, e.g. handwriting and recording;
- provides strategies to manage perceptual and sensory needs;
- advises on techniques to improve self-care skills, e.g. eating, dressing;
- develops vocational skills, supporting work experience and employment; and
- provides special equipment and guidance on building adaptations.

Physiotherapist

Physiotherapists work with young people, families and other professionals in their own homes, in school or in hospital. The physiotherapist:

- assesses range of movement, gait, postural control, respiration and mobility;
- provides exercises and activities for strengthening and maintaining range of movement and special equipment, if required;
- provides orthotic appliances, e.g. to improve walking;
- provides treatment in specialist settings, e.g. hydrotherapy; and
- helps young people take responsibility for their own fitness.

Speech and language therapist

Speech and language therapists support children, parents and carers in hospital and community settings, and in special and mainstream schools and colleges.

A major part of their work is working with teachers, parents and families support communication and help the child or young person access education. The speech and language therapist:

- assesses and treats children and young people with communication, speech and language needs or dysphagia;
- identifies the targets, strategies and level of support required to meet individual verbal and non-verbal needs, including alternative communication systems and communication aids;
- recommends positive communication environments needed within future placements; and
- helps young people to express their views and understand events in their lives, such as change of placement, through specific communication strategies and techniques.

Local authorities (children's services/adult services)

Connexions personal adviser

The Connexions personal adviser:

- provides information and guidance for young people between the ages of 14 and 19 and for disabled young people up to the age of 25;
- attends and contributes to the annual review and transition planning meetings in schools from Year 9 (age 14);
- offers young people and parents/carers advice about post-school and post-education options; and
- is responsible for overseeing delivery of the overall transition plan, liaising with others who have agreed to carry out actions, but is not responsible for arranging the specific provisions of other agencies.

From April 2008, responsibility for providing information, advice and guidance (IAG) services to young people passes to local authorities; schools and colleges will have the right to commission IAG from local providers including Connexions.

Educational psychologist

The educational psychologist:

- focuses on helping children with a range of learning and behavioural needs;
- assesses cognitive and learning abilities;
- may work directly with the child or young person but also consult with relevant adults; and
- supports the development of educational practice in schools and other organisations.

Social worker

Social workers are based in children's or adult services and cover a range of roles; the transition social worker (based in adult services) takes the lead, liaising with social workers from children's disability or looked-after (in care) children's teams.

Social workers:

- attend the annual transition planning meetings (from age 14) in school; and
- assess and organise provision to meet the care needs of the young person and their family.

Special educational needs coordinator

The SEN coordinator:

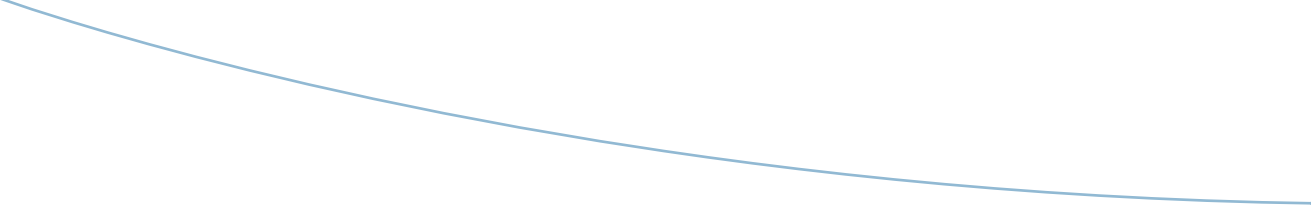
- records and updates information with regard to young people's special educational needs, whether or not they have SEN statements;
- liaises with parents and relevant professionals in other agencies;
- arranges educational facilities and resources;
- advises the teaching team, ensuring that individual education plans are in place;
- monitors young people's progress in educational settings, arranging formal reviews as required; and
- provides information about a young person's educational needs to key staff in further education settings.

Additional services

Learning and Skills Council

The Learning and Skills Council:

- is responsible for planning and funding post-16 education and training (not universities); and

- 
- has a statutory duty to fund provision for learners with learning difficulties or disabilities.

Non-statutory agencies

- Non-statutory agencies may be involved in providing generic or specialist support for young people.

Annex B: Transition plan – health

Name:

Address:

Date of birth:

Transition team (list all professions involved)	Name	Contact number

Start date __ / __ / __

Review 1 __ / __ / __

Review 2 __ / __ / __

Review 3 __ / __ / __

Review 4 __ / __ / __

Review 5 __ / __ / __

Review 6 __ / __ / __

A Word version of this plan is available at: www.dh.gov.uk/en/Policyandguidance/HealthandSocialCaretopics/Childrenservices/Transitionfromchildrenstoadulthealthservices/index.htm.

Young person's self-assessment

This document is designed to help you work with your healthcare team to manage your transition to adult services. You will work with the healthcare team to develop a plan that meets your needs as you begin to take more responsibility for managing your own health condition. This plan can change if your priorities change. Some of the statements on the health transition plan will not apply to you, so you can leave them out. Sometimes there will be things you want to add – there is space for you to do this. The most important thing is that you feel you are as involved in this process as you want to be. You can ask someone to help you complete the assessment.

	Yes	I need help with this	Action plan	Name of person taking action
Health transition				
I understand the meaning of transition to adult services				
I feel I am ready to start preparing for transition by developing a health plan				
I understand what confidentiality means, and that I should be involved in decisions about who knows about different aspects of my health condition				
I feel I need some support to explain my needs during clinic visits				
I feel I am ready to be seen alone for part of the clinic visit				
I feel I can be seen on my own in clinic				

	Yes	I need help with this	Action plan	Name of person taking action
I know the names and roles of the doctors, nurses and therapists I will be seeing in adult services and how to contact them				
I have agreed a transfer plan with dates with the members of the children's and adult healthcare team				
My specific health condition				
I can describe my health condition				
I know how to contact a support group for my condition				
I understand the medical terms/ words used in clinics				
I can answer questions from members of the healthcare team				
I can ask the doctor/nurse/ therapist questions				
I know who has copies of my medical records				
I keep a file with my health information in it				
I know when, where and with whom I have my next appointments				
I know the names and doses of my medicines and when to take them				

	Yes	I need help with this	Action plan	Name of person taking action
I am responsible for taking my own medication				
I can arrange for a repeat prescription of my medication				
My general health				
I know what to do if I suddenly become unwell				
I know how to contact my GP				
I know my GP can advise about different health issues including concerns about my development and mood				
I can cope with my everyday mood (e.g. feeling depressed), feelings (e.g. feeling anxious) and emotions (e.g. anger)				
I know what makes a good diet				
I know the benefits of a good diet				
I know the risks of a poor diet				
I know how to make an appointment with the dentist				
I know how often I should have a check up at the dentist				
I know about the benefits of an exercise programme				
I know the risks of not exercising				
I can manage to do any prescribed therapy exercises myself				

	Yes	I need help with this	Action plan	Name of person taking action
I know the risks of skin breakdown				
I know how to prevent skin breakdown				
My sexual health				
I understand the changes that happen to my body as I get older				
I know what I want to about sex and relationships				
I know where I can get accurate information about sex and relationships				
I know how to prevent pregnancy				
I know how to obtain and use contraception				
I know where to get advice if I become pregnant				
I know whether my medication could affect any pregnancy				
I know about sexually transmitted infections, how to avoid them and where to get treatment				
Other issues				
I know about the risks of smoking				
I know about the risks of drinking alcohol excessively				
I know about the risks of misusing legal and illegal drugs				

	Yes	I need help with this	Action plan	Name of person taking action
I know what to do if someone harms, threatens or otherwise behaves inappropriately towards me				
I know how to access websites for young people, including the Connexions website (www.connexions-direct.com/) and Teenage Health Freak (www.teenagehealthfreak.org)				

	Yes	I need help with this	Action plan	Name of person taking action
SELF-CARE SKILLS				
Dressing				
I get dressed by myself				
If you can't get dressed by yourself: <ul style="list-style-type: none"> • Has your care been reviewed so that you can become more independent? • Do you need referral to occupational therapy/rehabilitation services? • Does the amount of support you get and equipment you use need to be reviewed? 				
Eating and drinking				
I feed myself				
If you can't feed yourself: <ul style="list-style-type: none"> • Has eating/drinking been reviewed so that you can become more independent? • Do you need referral to occupational therapy/rehabilitation services? • Does the amount of support you get and equipment you use need to be reviewed? 				

	Yes	I need help with this	Action plan	Name of person taking action
Washing				
I wash myself and clean my teeth without support from my parents/carer				
If you can't wash yourself and clean your teeth:				
<ul style="list-style-type: none"> • Has washing been reviewed so that you can become more independent? 				
<ul style="list-style-type: none"> • Do you need referral to occupational therapy/rehabilitation services? 				
<ul style="list-style-type: none"> • Does the amount of support you get and equipment you use need to be reviewed? 				
Bathing				
I can bath/shower myself				
If you can't bath/shower yourself:				
<ul style="list-style-type: none"> • Has bathing been reviewed so that you can become more independent? 				
<ul style="list-style-type: none"> • Do you need referral to occupational therapy/rehabilitation services? 				
<ul style="list-style-type: none"> • Does the amount of support you get and equipment you use need to be reviewed? 				

	Yes	I need help with this	Action plan	Name of person taking action
Toileting/continence				
I can get myself to the toilet, clean myself and adjust my clothes				
If you can't use the toilet by yourself: <ul style="list-style-type: none"> • Has toileting been reviewed so that you can become more independent? • Do you need referral to occupational therapy/rehabilitation services? • Does the amount of support you get and equipment you use need to be reviewed? 				
Mobility				
I can get around indoors without help				
I can get over steps and kerbs without help				
I can get around outdoors without help				
I can use trains, buses and taxis without help				
I am learning to drive				
If you answered 'no' to any of the questions above: <ul style="list-style-type: none"> • Has mobility been reviewed so that you can become more independent? • Do you need referral to physiotherapy/rehabilitation services? 				

	Yes	I need help with this	Action plan	Name of person taking action
<ul style="list-style-type: none"> Does the support you get need to be reviewed? 				
Menstruation				
I can manage my periods by myself				
If you can't manage your periods by yourself:				
<ul style="list-style-type: none"> Has managing menstruation been reviewed so that you can become more independent? 				
<ul style="list-style-type: none"> Do you need referral to other services? 				
<ul style="list-style-type: none"> Do you need some extra help to manage this? 				
Home management skills				
I know how to buy food, clothes and other essentials				
I know how to manage a budget				
I can prepare a meal (food collection, preparation and storage)				
I can look after my own clothes (wash and iron)				
I can do light housework				
I know how to keep myself safe at home				
I would like to know more about the support and equipment that would allow me to do these tasks				

	Yes	I need help with this	Action plan	Name of person taking action
Housing				
I know about the range of options if I wish to live more independently				
If not, do you need advice?				
Education				
My teachers understand how my health needs affect my education				
(With support) I can manage my health needs in school/college				
I can get around the buildings at school/college				
I have the support/equipment I need at school to do the courses I want				
I would like my health team to meet with my education team				
I know how to ensure that my health needs are met if I move to a college or university				
Work/leisure				
I have a career plan				
I have had experience of work (voluntary or paid)				
I have been able to consider a range of career options				
I know how to discuss my health condition with a prospective employer				

	Yes	I need help with this	Action plan	Name of person taking action
Leisure				
I have friends my own age				
I can meet my friends regularly				
I have leisure activities that I enjoy				
I am able to try new activities				
I have goals for my future				
I know what support is available in my local community and which organisations can help				

Health plan summary

Name:

Address:

Date of birth:

Main health transition needs, discussed with young person (and their family):

1

Action

2

Action

3

Action

(Continue as required.)

Can the health plan be shared with other professionals/agencies? If only in part, please specify.

Yes No Signed(young person or parents/carers)

Health professionals involved	Referral made to children's health services	Referral made to adult health services
Clinical psychologist	<input type="checkbox"/>	<input type="checkbox"/>
General practitioner	<input type="checkbox"/>	<input type="checkbox"/>
Doctor(s) for specialties	<input type="checkbox"/>	<input type="checkbox"/>
Nurse	<input type="checkbox"/>	<input type="checkbox"/>
Occupational therapist	<input type="checkbox"/>	<input type="checkbox"/>
Paediatrician	<input type="checkbox"/>	<input type="checkbox"/>
Physiotherapist	<input type="checkbox"/>	<input type="checkbox"/>
Speech and language therapist	<input type="checkbox"/>	<input type="checkbox"/>
Child and adolescent mental health team	<input type="checkbox"/>	<input type="checkbox"/>
Learning disability team	<input type="checkbox"/>	<input type="checkbox"/>

Referral made to children's (education/social) services/adult (social) services

Connexions personal adviser	<input type="checkbox"/>	<input type="checkbox"/>
Social worker	<input type="checkbox"/>	<input type="checkbox"/>

Copy of health plan to:	<input type="checkbox"/>
Young person	<input type="checkbox"/>
Parents/carers	<input type="checkbox"/>
Involved health professionals	<input type="checkbox"/>
GP	<input type="checkbox"/>
Connexions personal adviser	<input type="checkbox"/>
Transition team coordinator	<input type="checkbox"/>
PCT commissioners	<input type="checkbox"/>

Annex C:

Audit of policy and procedures for the transition of young people from children's to adult health services

I. STRATEGIC DEVELOPMENT OF TRANSITIONAL CARE				
1	Is there a policy for young people within the trust?	Yes	No	Action
2	Does it take account of national guidance (including the National Service Framework for Children, Young People and Maternity Services and the You're Welcome quality criteria)?	Yes	No	Action
3	Is there a lead for young people undergoing transition within your trust?	Yes	No	Action
4	Is there a cross-agency lead for transition in your area?	Yes	No	Action
5	Is there a clear reporting mechanism to ensure that transition policy is discussed at board level?	Yes	No	Action
6	Are the implications of national transition policy and local strategy routinely discussed with health and local authority commissioners?	Yes	No	Action
7	Are health practitioners and commissioners represented on the local multi-agency transition strategy group?	Yes	No	Action
8	Is strategic information/updated policy disseminated to all practitioners working with young people in children's and adult services?	Yes	No	Action
9	Does local guidance include information about the roles of core health professionals?	Yes	No	Action
10	Have the needs of young people in transition been clearly specified?	Yes	No	Action

11	Has the core team of health professionals needed to support young people in transition been identified?	Yes	No	Action
12	Has a lead person been identified to develop transitional care across the organisation and/or in your service/specialty?	Yes	No	Action
13	Have working links with the local authority (education and social services) and Connexions personal advisers been set up?	Yes	No	Action
14	Has information about the roles of professionals supporting young people in transition been shared across agencies?	Yes	No	Action
15	Has transitional care been incorporated into business case planning for the service/specialty?	Yes	No	Action
II. DEVELOPMENT OF A TRANSITION POLICY				
	Ila General issues			
16	Is there a written policy in your service/specialty (health and/or multi-agency)?	Yes	No	Action
17	Does the policy include the safeguarding of children and young people?	Yes	No	Action
18	Is the importance of sharing information recognised within the policy?	Yes	No	Action
19	Is the confidentiality of the young person recognised in your transition policy?	Yes	No	Action
	Iib Stakeholder involvement			
20	Has the transition policy been discussed with young people?	Yes	No	Action
21	Has the transition policy been discussed with parents?	Yes	No	Action
22	Has the transition policy been discussed with multidisciplinary health team members?	Yes	No	Action

23	Has the transition policy been discussed with all key paediatric providers – community, generalist and/or specialist?	Yes	No	Action
24	Has the transition policy been discussed with key adult health providers?	Yes	No	Action
25	Has the transition policy been discussed with primary care?	Yes	No	Action
26	Has the transition policy been discussed with social services?	Yes	No	Action
27	Has the transition policy been discussed with education services?	Yes	No	Action
28	Have all stakeholders committed to sharing information where this does not conflict with the wishes of the young person?	Yes	No	Action
IIc Dissemination of policy				
29	Have key adult, as well as children's, providers been identified?	Yes	No	Action
30	Has the transition policy been disseminated to all relevant community and acute services (paediatric and adult)?	Yes	No	Action
31	Has the transition policy been disseminated to outpatients?	Yes	No	Action
32	Has the transition policy been disseminated to relevant ward areas?	Yes	No	Action
33	Has the transition policy been disseminated to key adult providers?	Yes	No	Action
34	Does every new team member of the transition team (medical, nurses and allied health professionals) receive a copy of the transition policy?	Yes	No	Action
35	Is the transition policy included in all induction packages for staff who may be working with young people and available in your department?	Yes	No	Action

36	Does your service/specialty provide specific staff training about confidentiality, consent and seeing young people on their own?	Yes	No	Action
37	Does your service/specialty provide staff training in generic adolescent health skills?	Yes	No	Action
38	Does your service/specialty provide staff training to ensure that attitudes and values are young people friendly?	Yes	No	Action
	IId Review of policy	Yes	No	Action
39	Do you have a regular date for reviewing your policy?	Yes	No	Action
III. COORDINATION OF TRANSITIONAL HEALTH PLANS FOR YOUNG PEOPLE				
	IIIa Coordination of transitional care			
40	Is there a named coordinator of transitional care in your specialty who has this role embedded in their job description?	Yes	No	Action
41	Is a lead clinician (key worker) identified for each young person?	Yes	No	Action
42	Is transitional care coordinated for young people using several health services or under multiple consultants?	Yes	No	Action
43	With permission from the young person, is the health plan shared between agencies?	Yes	No	Action
	IIIb Environment			
44	Does your specialty have a dedicated clinic for adolescents and/or transition?	Yes	No	Action
45	Are the waiting areas for young people comfortable and welcoming, with appropriate reading material?	Yes	No	Action
46	Is the environment in which you see young adults age-appropriate?	Yes	No	Action

	IIIc Liaison between children's and adult services			
47	Have target adult services been identified for your service/specialty?	Yes	No	Action
48	Is there information about key adult services available in paediatric clinics/children's services?	Yes	No	Action
49	Are appointments/clinics held jointly with adult providers?	Yes	No	Action
50	Are preparatory visits to the adult service arranged for patients prior to transfer in your specialty?	Yes	No	Action
51	Are patients offered an overlap visit to children's services following transfer to adult services?	Yes	No	Action
52	In your service/specialty, is transfer to the adult service a flexible process depending on the young person's needs?	Yes	No	Action
53	Is a transfer summary used to transfer key information from paediatric to adult services?	Yes	No	Action
54	Do young people receive a copy of this summary?	Yes	No	Action
55	Are young people invited to provide feedback about the service? (If yes, specify how.)	Yes	No	Action
IV. INFORMATION RESOURCES FOR YOUNG PEOPLE				
	IVa Specific			
56	Is there inter-agency, including health, information available about local transition policies and procedures for the young person and their family?	Yes	No	Action
57	Are specific age and developmentally appropriate information resources available for young people in your service?	Yes	No	Action

58	Is information available from support groups/ non-statutory organisations about specific conditions?	Yes	No	Action
	IVb General			
59	Are confidentiality and consent policies made explicit to young people and their parents/ carers through displayed information?	Yes	No	Action
60	Is there health promotion material available for young people about smoking cessation?	Yes	No	Action
61	Is there health promotion material available for young people about healthy eating and weight management?	Yes	No	Action
62	Is there health promotion material available for young people about alcohol use?	Yes	No	Action
63	Is there health promotion material available for young people about substance misuse?	Yes	No	Action
64	Is there health promotion material available for young people about mental health and emotional wellbeing?	Yes	No	Action
65	Is there health promotion material available for young people about sexual and reproductive health?	Yes	No	Action
66	Is there information available for young people about vocational and educational opportunities?	Yes	No	Action
67	Is there information available for young people about independent living, including mobility issues?	Yes	No	Action
68	Is there information available about health websites for young people?	Yes	No	Action
69	Is there an identified person responsible for the update of adolescent information resources?	Yes	No	Action

V. EVALUATION OF INDIVIDUAL HEALTH TRANSITION PLANS				
70	Is there any evaluation of transitional care in your specialty? (If yes, specify how.)	Yes	No	Action
71	Is a health plan proforma used in your trust/ practice?	Yes	No	Action
72	Are the young person's views/preferences central to the plan?	Yes	No	Action
73	Do plans address psychological issues?	Yes	No	Action
74	Do plans address social issues?	Yes	No	Action
75	Do plans address independent living issues?	Yes	No	Action
76	Do plans address vocational/educational issues?	Yes	No	Action
77	Are young people actively involved in developing the plan?	Yes	No	Action
78	Is a lead clinician identified as the health plan coordinator for each young person?	Yes	No	Action
79	Are parents/carers included in developing the health plan?	Yes	No	Action
80	Do young people receive a copy of their health transition plan?	Yes	No	Action
81	Is the health plan (or copy) kept in the medical notes?	Yes	No	Action
82	Is the health plan (or copy) kept in the nursing notes?	Yes	No	Action
83	Is the health plan (or copy) kept in the therapy notes?	Yes	No	Action
84	Is the health plan (or copy) kept in the CAMHS notes (if appropriate)?	Yes	No	Action
85	Are health plans reviewed on a regular basis (with dates set) and actions checked?	Yes	No	Action

A Word version of this audit is available at: www.dh.gov.uk/en/Policyandguidance/HealthandSocialCaretopics/Childrenservices/Transitionfromchildrenstoadulthealthservices/index.htm.

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