

a transition guide for all services

key information for professionals
about the transition process for
disabled young people

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All young people have dreams and aspirations, including disabled young people. The following poem captures that aspiration and is one of many written by Leon Jordan, who is featured on the front cover of this guide.

Fly high

by Leon Jordan

Where is my pork pie?
Spread those wings and fly high
We say the sky's the limit
You can do it
Orpheus could play the lyre
Aim higher
Reach for the sky
Focus on positivity and fly high
The security is tight
You and your dreams have taken flight
The towels are dry
Ram like an arrow pulled far, I fly
The sky looks grey
We shall succeed one day
Sad things make us cry
Follow your dream and fly

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This handbook is intended as good practice guidance on the roles, responsibilities and duties for all service providers working with disabled young people (including those with complex health needs) through their transition to adulthood. The guide includes references to and brief explanations of relevant legislation but these should not and cannot be treated as authoritative interpretations of the law. Service providers should continue to seek advice of their legal advisers on matters of interpretation and, where necessary, the courts. The content in the guide is drawn from a wide range of contributors and does not necessarily reflect the views of either the Council for Disabled Children, the Department for Children, Schools and Families or the Department of Health.

The examples and checklists included in the document have been developed by local authorities and partner agencies or by the Council for Disabled Children to illustrate the main text. Extracts from this document may be reproduced for non commercial or training purposes on the condition that the source is acknowledged.

Cover photo of Leon Jordan by Transition Information Network.
Many thanks to Leon for his poem.

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Ministerial foreword

The report *Aiming high for disabled children: better support for families* (DfES/HMT 2007) emphasized the Government's commitment to improving the life chances of disabled children and young people, whose needs are often complex, not well met or overlooked altogether. This guide provides an overarching view of all the services that need to work together to make sure that disabled young people get the support they require as they move from child, to young person, to adult. In many instances their transition into adulthood will require careful preparation and intricate packages of support put in place to help them.

Our expectation is that this guide, together with *Transition: getting it right for young people*, which we published in 2006 and the specific guidance being published for health professionals and their partners, will provide a comprehensive map of the requirements, expectations and current good practice on transition at local level. Existing practices need to be built upon to make transition for disabled children and young people a fulfilling experience. Getting transition right for disabled children and young people has positive benefits not just for them but their family and friends too.

We urge local service providers to take advantage of the momentum being provided by the Aiming high initiatives and the Transition Support Programme in particular, which is being developed and rolled out across the country between 2008 and 2011 to work efficiently and effectively together.

We owe it to all young people to enable them, with appropriate assistance and support, to move along their particular path, towards adulthood and future independent living.



A blue ink signature of Andrew Adonis, written in a cursive style.

Andrew Adonis



A blue ink signature of Ivan Lewis, written in a cursive style.

Ivan Lewis

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This resource has been designed to offer the most up-to-date information on the transition process. As legal duties change or new guidance is produced, information on these and the latest practice will be available from the Transition Information Network (TIN) and the Every Child Matters websites. If you have practice, resources or ideas you would like to share, please send them to TIN@ncb.org.uk in the first instance to be added to the national database.

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Introduction

The transition from school to adulthood is a time of celebration, change and challenges for all young people. They will be considering and making decisions about their career, their continuing education, their social life and where they will live. For many disabled young people and those with special educational needs (SEN),¹ having access to timely and comprehensive information, advice and guidance can be enough to help them reach their goals. For others, more support may be needed from a range of services to enable them to reach their full potential.

Currently, support available locally for disabled young people and their families varies widely. Services are struggling to provide timely support, share expertise and work together effectively to support this group of young people. It is essential that joined-up and comprehensive services are available throughout the transition process that will enable disabled young people to grow up and live the lives they want, to fully participate and be active members of their community.

Definitions of disabled young people

Using the definition from the Disability Discrimination Act 1995, the population of disabled children and young people across the four nations of the UK currently stands at over 770,000² and the evidence suggests this number is rising. This rise is due to a number of factors, including increased survival of pre-term babies and greater numbers of children being identified with autistic spectrum disorders. Furthermore, among this population there is a growing proportion of children with complex and significant needs; for example, there are more than 6,000 children in Britain dependent on assistive technology.³

More children with complex health needs are surviving into adult life; therefore, transition is an increasing issue for all services. These groups, along with those with SEN, have a wide range of support needs. Although the number of pupils with statements of SEN remains at just under 3 per cent of the pupil population in England, the number of pupils with SEN and no statement is over 16 per cent pupils across all schools.⁴

These groups include disabled young people with complex health needs, those who are looked after, and those from black and minority ethnic groups, who face further discrimination. In the past, young people from these groups have not had access to the support they need. Disabled young people need support to access work experience placements, find college courses and employment, use local leisure facilities and find a home of their own.

1 We use the term 'disabled' in this publication to mean all young people with disabilities and SEN, and those without a diagnosis or Statement of SEN, but who require support through School Action and School Action Plus. Exceptions to this are stated in the text.

2 *Improving the life chances of disabled people*, 2005, Cabinet Office, p5

3 National Service Framework for Children, Young People and Maternity Services, 2004, Standard 8, Department of Health (DH) and DfES, p7

4 In 2007, 229,100 (2.8 per cent) of pupils across all schools in England had statements of SEN. In 2007, there were 1,333,400 pupils with SEN without statements – 16.4 per cent of pupils across all schools. (*Special Educational Needs in England*, Reference ID SFR20/2007, 2007, DfES National Statistics)

Why is transition so difficult to get right?

The transition to adulthood is an all encompassing process covering every aspect of a young person's life. Supporting disabled young people in their transition to adulthood can be a challenge to service providers. This is because the process must be individual to the needs and aspirations of each young person. It is a fluid process, spread out over a number of years, and often local options for disabled young people are limited and support can be patchy and inconsistent. These challenges are compounded by young people's moves from one service to another at different ages. For example, a disabled young person may move from paediatric to adult health services at 16, then at 18 move from children's to adult social care. This is alongside the transition stages in their education. Each of these transitions is likely to occur independently of each other, which means that disabled young people and their families may repeatedly have to deal with new agencies and professionals, re-telling their story each time.

Not all disabled young people receive support from social care services, but a significant number do. Many of this group however, face stringent eligibility criteria set by social care services to manage their limited resources. The result is that disabled young people can miss out on critical support because different eligibility criteria apply when they move on to adult services. They may then find they are not eligible for services that could provide timely and effective support for them or their family.

Moving forward

To make sure disabled young people get the support they need as a matter of course, all agencies need to make two activities a priority:

- listen to what disabled young people say they want
- work positively together across agencies.

These priorities underpin much recent policy and legislation, including:

- *Improving the Life Chances of Disabled People*, 2005 Cabinet Office
- *Removing barriers to achievement: the government's strategy for SEN*, 2004 DfES
- *Every Child Matters: Change for Children*, 2004 DfES
- *National Service Framework for Children, Young People and Maternity Services*, 2004 DH and DfES
- *Youth Matters/Youth Matters Next Steps*, 2005/6 DfES
- *Learning for Living and Work*, 2006 Learning and Skills Council (LSC).
- *Aiming high for disabled children: better support for families*, 2007, HM Treasury and DfES

All of these documents emphasise the need for children and young people to be at the centre of plans made to support them, for agencies to work together to ensure effective working practice, and for a commitment to ensure that disabled young people are given a real range of choices for their future.

The following chapters illustrate some of the ways in which service providers can make statutory duties work most effectively to provide support in all aspects of the transition to adulthood, for disabled young people and their families.

This guide is a starting point to give all services useful information and examples of excellent support for disabled young people and their families. Legislation, guidance and structures affecting the transition process are changing and services are adapting in different ways.

To accommodate the needs of all disabled young people who would benefit from support as they move into adulthood, this guide covers basic legal requirements and effective practice.

For updates, further case studies and resources please go to www.transitioninfonet.org.uk

The transition process

Developing a strategic transition protocol

Developing a local transition pathway

Transition reviews

Post-16 options: education and employment

Person-centred approaches

Developing a strategic transition protocol

*'a key problem leading to lack of continuity in provision across transition stems from the different entitlement criteria and definitions between child and adult services.'*⁵

? Who

Disabled young people, families, directors of children's services, directors of adult services, primary care trust (PCT) leads, disabled children's service managers, education officers (local authority), Connexions managers, lead members, other health trusts (especially acute hospital), primary care leads (GP commissioning)

? Where

Children and Young People's Strategic Partnership Board (CYPSPB) and subgroups, children's services, adult social care services, Connexions, Learning and Skills Council (LSC), PCT, Child and Adolescent Mental Health Services (CAMHS), Jobcentre Plus, education forums, children's and adult health services

Introduction

Developing a clear, strategic, multi-agency, agreed protocol on how local services work to meet the needs of disabled young people in their transition to adulthood can transform the effectiveness of local support. Evidence from the pathfinder stage of children's trusts development clearly shows that in areas where time was taken to develop agreed strategies across agencies the ensuing work and services were improved.⁶ Most areas will already have some strategic agreements in place about who provides which services for disabled young people and their families at transition. It is important to regularly review these agreements to ensure they are still relevant to each agency and still meet the needs of the local population.

Transition planning at a strategic level

Most local authorities have a strategic planning group for transition linked into the Children and Young Peoples Strategic Partnership Board (CYPSPB) and Learning Disability Partnership Board (LDPB). This is the main group responsible for developing and producing a multi-agency transition protocol.

Brighton and Hove have a transition forum to serve this purpose. The forum reports into children's services and to the LDPB so that adult services and planning are also informed.

⁵ *Improving the Life Chances of Disabled People*, 2005, Cabinet Office

⁶ *National Evaluation of children's trust arrangements*, September 2005, University of East Anglia

Like transition itself, developing and reviewing a protocol is an ongoing process which needs to be monitored and evaluated regularly. The transition planning group needs to include a representative number of local disabled young people and their families, representatives from children's services, adult social services, health services, local colleges and the Connexions service as a minimum. It may also have representatives from other agencies including the Children's Information Service, independent schools and leisure services. In most areas, this group meets a few times a year to discuss how local provision is working and how it can be improved. Some local areas have access to regional transition networks, supported by regional partnerships, which offer a forum to share practice and learning with a wider group. See Appendix 4 for an example.

Effective practice

The process of bringing a group of appropriate people together to plan, agree and implement a local strategic transition protocol is in itself a challenging piece of work. Each agency has a range of different goals and priorities at any given time so bringing the right people together can take time and commitment. It is therefore crucial to have a person and agency leading in this process.

Sandwell

A Transition Team Manager, employed by Prospects Services Ltd, funded through Black Country Connexions has established a multi agency Transition Team to support disabled young people through their transition from education to post 16 options. The manager set up and chaired a multi agency Transition Steering Group, took on the role of Transition Champion for Sandwell Learning Disability Partnership Board and promoted the regionally developed Transition Pathway with all agencies.

The Transition Manager chaired a sub group with representatives from the SEN team, mainstream and special school staff and mainstream and LDD Connexions Personal advisers to develop joint guidelines to be used in transition planning within Sandwell. The SEN team purchased copies of the Transition Pathway materials for all schools and multi agency training sessions on the use of the Transition Pathway materials and on the joint guidelines was delivered in July. Use of the materials and planning processes have been recommended to all schools.

Prospects have put together guidelines on the role of the Connexions Personal Advisers which incorporates the use of the pathway's person-centred 'Getting Ready Sheets' to use with young people in their work.

Data collection

Schools, children's services, adult social care services, Connexions and the LSC all have a role to play in gathering and sharing information to support disabled young people and their families. By working together on this, agencies can greatly reduce the number of different assessments a disabled young person at transition may have. Having local agreements on using a person-centred approach and sharing assessment information where possible means that less time will be taken up with assessing young people and agencies can make more effective use of resources. For more information on the current range of assessments, see Appendix 3. Using person-centred approaches is covered on page 20 in detail.

As use of the common assessment framework becomes more widespread, agencies will be able to share basic information without compromising confidentiality and respond better to local need. For more information on the common assessment framework and Contact Point (Integrated systems) see www.everychildmatters.gov.uk.

Northumberland

Northumberland Care Trust (adult social care services for Northumberland), Northumberland County Council's Fair Access to Care implementation team and Connexions Northumberland are piloting a system for data sharing at transition to ensure that adult care services know who is likely to need support in future. At the Year 9 review, a set of seven simple and brief questions is posed (focusing on levels of ability). If the answers imply that the young person may need adult services in the future, their details will be added to the database. Adult services will then contact the young person and their existing care managers and work with them to plan for the future.

Quality standards checklists

Having every local agency making a clear commitment to provide specific support to disabled young people and their families throughout the transition process is essential. Checklists A1 and A2 in Appendix 6 outline what local authorities and their partners can do to develop effective protocols.

Key legislation, guidance and resources

see page 8

Developing a local transition pathway

*'Pathways lay out the steps involved in transition and show who is involved at each stage and what the options may be at each stage. They are useful as they show clearly what the steps are and who has responsibility. They make what is a complicated process look manageable and comprehensive.'*⁷

? **Who**

Disabled young people, families, children's social workers, transition social workers, adult team social workers, Connexions managers and personal advisers (PA), healthcare and therapy staff, Jobcentre Plus advisers, head teachers, school staff, information and advice workers, speech and language therapists (SLT),

? **Where**

Strategic transition groups, children with disabilities teams, local authority education, schools, colleges, LSC, Connexions services, community nursing teams, physiotherapy services, occupational therapy services, Jobcentre Plus, adult social care teams, CAMHS, Children's Information Services

Introduction

Once a strategic protocol is agreed and in place, it needs to be translated into something everyone concerned with the transition process can understand and act upon. Many areas have developed a transition pathway to do this. A pathway gives the protocol operational detail and is very effective in mapping out how local services and individuals within them can work most effectively together to support disabled young people and their families. The process is time consuming and needs an identified lead to take it forward. However, time spent working out and gaining agreement on how the protocol will be translated into a pathway to work in practice can make a significant difference to service quality.

Developing a pathway

At the core of each transition pathway will be the legal duties of each statutory service. The most effective pathways have input from disabled young people and their families and from a range of other agencies likely to be providing support or services during the transition process. These will include Jobcentre Plus, leisure services and transport. Chapter 2 has details on what each agency should provide.

Many areas have a multi agency transition group which meets regularly to develop the pathway and work with all agencies, families and disabled young people to monitor and improve local support. This group is often a 'sub group' of the LDPB or the CYPSPB. This group may be chaired by a Transition Champion who will act as a point of contact for transition issues within the local authority area.⁸

⁷ Getting a Life, Summer 2005 edition, Council for Disabled Children

⁸ The 'transition sub group' and role of 'Transition Champion' were first set out in the *Valuing People* white paper. For further information see www.valuingpeople.gov.uk

Effective practice

Appendix 4 shows a transition pathway set out as a flowchart, which is a common and effective way to illustrate key actions and responsibilities across local agencies.

Further examples of effective practice are available from www.transitioninfonetwork.org.uk

Quality standards checklist

Like transition protocols, operational pathways have a set of key characteristics which support their effectiveness. Checklist A3, A4 and A5 in Appendix 6 outline these characteristics.

Key legislation, guidance and resources

Sections 10 and 11 of the **Children Act 2004** set out the framework under which agencies which have responsibility for, or engage in activities relating to, children, must cooperate and put in place arrangements to safeguard and promote the welfare of children. Section 12 covers sharing of information about children to that end. Section 17 requires children's services authorities to prepare and publish a strategic plan setting out how services for children and young people will be provided; the Children and Young People's Plan (CYPP). Although authorities awarded four stars in the Audit Commission's comprehensive performance assessment⁷ are not required to produce a plan, it is widely recognised as good practice to do so. The protocol for the transition to adulthood of disabled young people should be part of this plan.

Children and Young People's Plan (England) (Amendment) Regulations 2007
<http://www.opsi.gov.uk/si/si2007/20070057.htm>

Improving the Life Chances of Disabled People, 2005, Cabinet Office

Transition Pathway: Guidance and tools to support person-centred transition planning with young disabled people aged 13–25, 2005, Scholl, C et al.
www.transitionpathway.co.uk

Pathways to Success, good practice guidance for children's services in the development of services for disabled children, 2006, Council for Disabled Children (CDC)

Transition: A Professional's Guide to Good Practice in the East of England, 2005, updated November 2006, East together – Eastern Region Partnership

Further information on legislation and guidance can be found in the resources pages at the back and in Appendices 1 and 2.

Transition reviews

*'A distinguishing feature of the transition process for disabled young people as opposed to their non-disabled peers, is often the very public and bureaucratic nature of the decision making processes. At a private level the processes are similar for disabled and non-disabled people alike.'*⁹

? **Who**

Disabled young people, families, head teachers, Connexions PAs, key workers, lead professionals, advocates, educational psychologists, speech and language therapists (SLT), physiotherapists, occupational therapists, children with disabilities social workers, transition social workers, adult team social workers, housing officers, transport contacts

? **Where**

Schools, Connexions services, children's services, health services, adult social care services, CAMHS, housing, transport services

Introduction

Having a review that leads to a transition plan that clearly sets out the wishes and aspirations of individual disabled young people as well as the support that they need, is a highly effective tool. The plan sets out the commitment each agency has made, and how and when the support will be delivered. It also enables young people, their families and professionals to keep a track of the complex process, review the support and plan what support will be needed in the future.

Many young people who would benefit from a review do not fall into the definition of 'SEN' or 'disabled' that would trigger the statementing process. It may, therefore, be helpful in practice to adopt the principle of assessment and annual review with those young people requiring extra support as a matter of course to ensure their needs are set out and met consistently. When carried out well, this process can help provide young people with the support they need, when they need it, so they can achieve their aims and independence as adults.

Review process

It is crucial that professionals understand their role in transition review meetings and how they can work with other agencies to support young people as they plan for their future. The annual review of a statement of special educational need (SEN) in Year 9 includes a transition review and starts the formal planning part of the transition process for young people with statements of SEN. This annual transition review process will continue until they leave school.

The transition review should cover areas the disabled young person thinks are important and be based on their individual goals rather than centred around available existing services. The review should cover at least the following areas:

- their ideas, aspirations and concerns about their future – including friendship, social activities, etc

9 Improving transition planning for young people with special educational needs, 2006, Lesley Dee, Open University Press/ McGraw Hill

- their progress at school, achievements, and plans to strengthen their skills
- changing support needs (including health, transport, CAMHS, preparing for adult life)
- objectives for the following year
- starting to plan how they may achieve their aspirations and the support they will need to do this.

School head teachers have responsibility for calling the transition review meeting and drawing up the transition plan. Further information about this process is on page 30 in Chapter 2. The Connexions service must attend the year 9 review as a condition of their grant, and may oversee the drawing up of the transition plan. These meetings need to cover a wide range of issues, such as practical considerations for further education (FE), employment or other options. Professionals at the meeting also need to listen to the wishes of the young person, which may include anything ranging from using local leisure activities, to finding housing or travelling the world.

Support from the Connexions service

In the final year of compulsory education as part of this process, all young people with statements of SEN who are believed likely to leave school to go on to post 16 education and training must have a Section 140 assessment (Learning and Skills Act, 2000, S140). This is carried out by the Connexions service, which produces a written report of the young person's educational or training needs and the provision required to meet them.

The Section 140 assessment is designed to build on the framework of other assessments rather than duplicate them. Where the Connexions PA has been fully involved in the transition planning process from the initial Year 9 transition review they should have most of the information they need to complete the assessment by the time the young person is in Year 11.

The section 140 Assessment should help the Learning and Skills Council and post-16 provider put in place the support the young person needs to achieve new goals.

Current developments

As the funding for the provision of information, advice and guidance will be moving from Connexions partnerships to local authorities from 2008, it is likely that in some areas the role of Connexions will alter. The statutory assessment process outlined above will, however, remain the same. For further information see Appendix 3 on Assessments and www.connexions.gov.uk.

Children's and adult social care services

A representative from children's social care services should attend the Year 9 review if the disabled young person is in receipt of services. If it is likely they will need support in future from either children's or adults social care services, the service should be informed.

Disabled young people with looked after status

National statistics from 2005 show that on any one day there are approximately 60,900 looked after children in the UK.¹⁰ Of these, 2,400 are recorded as being disabled. But according to research commissioned by the DfES and published in 2005, there are approximately 13,300 disabled children in long-term residential placements in education, social care and health settings.¹¹ The social care teams who work with disabled children and those who work with looked after children need to maintain good links to ensure the needs of this group, particularly those placed out of area are met. Disabled young people who are looked after may need extra support on their options about living arrangements, continuing their education, and employment as they make the transition to adulthood. It is, therefore, particularly important for this group that transition planning starts in Year 9, to ensure enough time is available to plan for the necessary support and resources.

The White Paper *Care Matters: Time for Change* published in June 2007 will have an impact on this group. It sets out the Government's plans to, among other things, provide young people with the opportunity to benefit from staying with their former foster carers and to provide leaving care personal adviser support for those who haven't achieved the qualifications they need by the age of 21 as well as those young adults who request additional support up to 25. See www.everychildmatters.gov.uk for further information.

Local health services

A significant number of disabled young people are likely to be receiving services from a range of health professionals. This could include a paediatrician, speech and language therapist, occupational therapist, GP and physiotherapist. These health professionals have a key role in the transition planning process. This includes providing information on current health needs and possible future health support. They are required to submit written information to the Year 9 review and, where needed, attend.¹²

Taking part in the Year 9 review provides an opportunity for health services to start thinking about the transfer to adult healthcare services with the disabled young person and their family. These preparations either with GPs or in paediatric and adult health services need to be phased over a period of time to allow young people to adjust. They also need to be part of the formal transition review to ensure the process is joined up.

The use of health action plans (or health plans) can provide a useful focus to bring together planning for all aspects of support from a range of health services. This too should be part of the main transition review process. See Appendix 4 for more information on health action plans.

10 *Children Looked After by Local Authorities, Year Ending 31 March 2005*, <http://www.dfes.gov.uk/rsgateway/DB/VOL/v000646/index.shtml>

11 *Disabled children in residential placements, November 2005*, Anne Pinney, independent researcher, commissioned by DfES

12 Education Act 1996

Confidentiality

Many professionals hold information about disabled young people. This information is invaluable in the transition review process to plan how to provide more effectively the support that disabled young people and their families want and need. However, the sharing of information among agencies needs to be carried out within reasonable limits and shared only where it is of direct use in the process and with the agreement of the disabled young people and their families.

Effective practice

The transition review process must be effectively implemented. The process in itself is meaningless if the actions agreed are not followed up. The transition plan should inform:

- curriculum planning to help disabled young people with a range of needs to achieve in school and prepare for choices afterwards
- planning for access to health services beyond those related directly to a young person's disability, for example, contraception, advice on healthy eating, etc
- the LSC and planning for local colleges.

The transition plan needs to be an active document with the disabled young person at the centre of its development and implementation.

Disabled young people attending the review

The organisation of and preparation for review meetings should be centred on disabled young people's needs and how they will be supported to fully participate in the review process. For example, the meeting coordinator should find out where and when the young person would like to meet, who they would like to be present and how they would like to communicate their views. For families, the meeting format, style and timing need to be organised so they feel confident about contributing. Transition reviews need to be carried out in a person-centred way (see page 20 for more details on person-centred approaches).

A small number of authorities have developed a range of communication frameworks for disabled young people, including using multimedia equipment to record their views and wishes to be shown at their transition review meeting if they do not want to attend. Such methods are also used with disabled young people who have complex communication needs. They can pre record their views and have them played at the meeting to convey what they want to say.

Westminster

Disabled Young People in transition to adulthood have the opportunity of working with **Paddington Arts Multimedia Profiling project**, which encourages people with learning disabilities to use multimedia to document areas of importance in their lives. Young people have made videos of their lives, everything they like doing, people who are important to them and so on, which are played in

the transition review. Sometimes young people attend the review and speak as well as show their video, and sometimes young people choose to not go the review but are happy that their view is still being listened to. The Multimedia Profiling worker from Paddington Arts works closely with local authority staff to ensure that their work is meeting the needs of disabled young people. For more information go to www.paddingtonarts.org.uk.

As a result of the transition review meeting in Year 9, actions should be agreed between the young person, their family, the school and other relevant agencies. On the basis of this, the head teacher has responsibility for drawing up a plan that clearly defines who is responsible for what and when actions should be taken. Currently, the Connexions service has a responsibility for overseeing the delivery of this transition plan. This plan must be reviewed and updated each year, in consultation with the disabled young person and their family.

Out-of-area placements

Some disabled young people attend special schools or are looked after outside of their local authority area. For this group, the transition planning process will involve the school they attend and any local health services they are receiving, as well as their placing local authority. The process will also involve the Connexions service local to their school and the one in their local area. The head teacher will be the person responsible for notifying the placing authority of the upcoming transition review. This can present particular issues for staff wanting to support disabled young people. Travelling, sometimes considerable distances, to visit and then attend the transition review, proves to be a real challenge for staff from all agencies. Where young people are looked after it is important that the transition planning process is co-ordinated with the statutory process for reviewing the looked after care plan. This is essential in ensuring that disabled young people get the support they want and need. With this in mind, a number of local authorities have developed 'home and host' arrangements. The example below from Westminster illustrates how this can work where Connexions acts as the lead agency.

Young people in placements outside of Westminster

It is expected that the Connexions PA linked to the out-of-borough ('host') placement will provide the ongoing support for the young person and their family. However, the Westminster Connexions PA in the young person's home area should work closely with their 'host' colleague and also attend annual reviews where necessary (e.g. Year 9 and Year 11) to ensure the transition process is running smoothly.

The Connexions PA will need to ensure that the transition plans for those disabled young people in schools out of borough are brought to the attention of the Young People's Transition (YPT) operational group for future planning of supportive services following the young person's 18th birthday.

The Connexions PA should seek the agreement of young people and their families to share information with the YPT group.

For those young people known to Westminster Children and Community Services and placed in schools out of borough, the allocated social worker will ensure that the appropriate links are in place for planning the young person's continuing support services once they leave school.

Person-centred approaches in transition reviews

In using a person-centred approach in transition planning, professionals can support disabled young people to express what they would like to happen in their future, on their terms. For the purposes of the formal transition review process, this means putting the disabled young person at the centre of the process. They should not only be invited to the meeting, but their plans, ambitions and worries should form the focal point of it. More on person-centred approaches can be found on page 20.

'And they listened ...' Family views about doing transition reviews the person-centred way

Young disabled people and their families taking part in a pilot of person-centred transition reviews in Calderdale all agreed that the person-centred format was a big improvement on traditional reviews. Families found the review very positive, open and transparent. They felt more confident with an independent facilitator keeping the focus, making it easier for them to contribute. Meeting the facilitator and the Connexions personal adviser before the review helped everyone to prepare. One parent found it easier to write things down than to speak in front of everyone.

'I felt the school had a different picture of Felix because of the review. They listened to him saying what he wants to do and seemed more motivated to support him to achieve his ambitions.'
Parent

Using the action plan as the focus of the review helped keep everyone on track. Parents stressed that implementation of the action plan was the real key to making a difference to their son or daughter's life.

A recurring request from families was to have a key worker responsible for coordinating the many changes that occur as young people plan to leave school and beyond.

For further information: www.valuingpeople.gov.uk

Further examples of effective practice are available from www.transitioninfonet.org.uk

Quality standards checklists

Checklists A6 to A12 in Appendix 6 are designed to help agencies meet their duties in supporting disabled young people and their families through the transition process and to further check their services are meeting local need.

Key legislation, guidance and resources

Education Act 1996

Education (Special Educational Needs) (England) (Consolidation)

Regulations SI 2001/3455 substantially amended by SI 2006/3346

Children Act 1989

Children Act 2004

NHS and Community Care Act 1990

Disabled Persons (Services, Consultation and Representation) Act 1986

Learning and Skills Act 2000

Data Protection Act 1998

Care Matters: Time for Change White Paper, 2007, DfES

Special Educational Needs Code of Practice, 2001, DfES

SEN Toolkit – Section 10: Transition Planning, 2001, DfES

Common Assessment Framework: Managers' Guide and

Practitioners' Guide, 2006, DfES. www.everychildmatters.gov.uk

Valuing People: A New Strategy for Learning Disability for the 21st Century, 2001, Department of Health

Future Positive – A Resource Guide for People Working with Disabled Care Leavers, 2006, DfES

Further information on legislation and guidance can be found in the resources pages at the back and in Appendices 1 and 2.

Post-16 options: education and employment

'All my colleagues accepted me, accepted me as a person not as a disability. That was one thing I was really surprised at. I actually felt that the workplace treated me better than anywhere ever had ever done, not including my college.' Dave aged 18¹³

? Who

Disabled young people, families, connexions personal advisors, SENCOs, disability employment advisors/brokers, college access officers, work placement coordinators, therapists

? Where

Further education (FE) and sixth form colleges, higher education (HE), school sixth forms, work-based learning providers, specialist colleges, colleges, universities, day centres, Jobcentre Plus, Connexions offices/centres, local employers, work placement centres

13 *The RITE transition: the only way forward*, 2006, Dare Foundation and Ace Centre

Introduction

Planning for the future should be based on the wishes and goals of individual disabled young people. This could mean being supported to choose, as individuals, what they want to do next rather than having to choose from existing local options. Whatever choices disabled young people make about their future, having good access to support and information about possible options is essential. Professionals working with disabled young people need to be able to respond to their questions about post-16 options and be able to signpost them to sources of more detailed information that will help inform their choices.

In considering options for young disabled people, alternatives to work and education should be considered where this is more appropriate for the individual to realise their aspirations. Options such as accessing community activities, resources and facilities or voluntary work opportunities can provide positive alternatives and enable them to have a more appropriate range of experiences.

Many disabled young people will move from school into further education, training or employment. Appendix 5 outlines the range of benefits and funding for education that may be available to disabled young people when they reach 16.

Current developments

At the time of writing, a number of proposals to change the education system to better support all young people to move from compulsory education into further education, training or employment are out for consultation. This includes a review of 14–19 provision, and raising the school leaving age. These and other developments could have a huge impact on disabled young people's experiences at transition.

See www.dcsf.gov.uk for updates.

A cross-Government review of policy on Independent Living for disabled people is currently taking place. The review is expected to report in autumn 2007 and make recommendations on support from: health; social care; transport; employment and housing. In addition to this review, the Disabled Persons (Independent Living) Bill is making progress through the parliamentary process. Further details on the review from www.dwp.gov.uk, and on the bill from <http://bills.ais.co.uk>.

Types of post-16 education provision

Staying on at school

Young disabled people may wish to continue their education in their current school, whether this is a mainstream or special school. If their current school does not offer the range of courses they want to study, they can choose to continue their education at a different school.

Going to further education or sixth form colleges

FE and sixth form colleges offer a wide range of courses including A levels and vocational (work-related) courses as well as courses that develop daily living, communication and employability skills. They receive most of their funding from government via the funding council (e.g. LSC). Colleges are no longer attached to a particular local authority.

Going to a specialist college

There are a small number of specialist colleges, many of which offer residential places. Some disabled young people and their families may decide a specialist college gives the best range of options for them. They generally have established support in place to meet the needs of a range of students.

Work-Based Learning (WBL)

Apprenticeships Work-based training programmes give young people the opportunity to work for an employer, earn a wage and gain qualifications, knowledge and skills. There are no entry requirements but young people need to be living in England and be aged between 16–18 and not participating in any form of post-16 learning. For more information see www.lsc.gov.uk.

Entry to Employment (e2e) This programme aims to help young people gain the skills they need to get a job, go into FE or get an apprenticeship. Young people aged 16–18 who go onto E2E may be able to receive an EMA. Their parents will also be eligible to claim Child Benefit for them, and may also be eligible for Child Tax credits. Study leads towards a level one or entry-level qualification and young people can improve their numeracy, literacy, employability and independent living skills. For more information, see www.lsc.gov.uk.

Programme-led Pathway courses These courses prepare young people to progress on to an employer-led apprenticeship. They can be delivered through FE, normally on a full-time basis, or on a vocational course where subjects studied form one or more parts of an apprenticeship framework, or to non-employed learners on apprenticeships funded through WBL. For more information see www.lsc.gov.uk.

Personal and Community Development Learning This provision can be delivered by various providers such as local authorities, workers' education association, trade unions, or community, voluntary or faith groups. Learning itself can take place in a variety of settings such as dedicated centres, FE colleges, schools, community centres, pubs and churches. For further information see www.lsc.gov.uk.

Types of work

Supported employment

This focuses on placing disabled people in employment and training which leads to long-term employment. The British Association for Supported Employment (BASE) has over 200 supported employment agencies as members and offers sources of advice for supported employment in different areas across the UK. For more information go to www.afse.org.uk.

Access to Work

Disabled young people who are in work may be able to claim support from the Access to Work initiative, which can provide equipment and a wide range of other services to support them in their job. The disability employment adviser (DEA) at the Jobcentre Plus office can put young people in touch with the closest Access to Work Business Centre. For more information see www.jobcentreplus.gov.uk.

Sources of careers advice

- The Connexions service provides careers information and advice and is available for young disabled people between the ages of 13 and 24 years. www.connexions.gov.uk
- The Nextstep service is funded by the LSC and is available to adults age 20 and over. Eligibility may depend on current qualification levels. Services include information and advice on choosing a career and the provision of guidance software such as Adult Directions. www.nextstep.org.uk
- Learn Direct is a national organisation which provides a number of services, including information about course providers and qualifications needed to pursue particular careers. It can also direct young people towards further sources of careers advice. www.learndirect.co.uk
- Disability Employment Advisors (DEAs) at Jobcentre Plus offices can complete a work assessment to help young people identify the type of work they would like and what they need to do to get it. www.jobcentreplus.gov.uk

Current developments

Learning for Living and Work, the LSC national strategy for its funding and planning of provision for disabled learners was published in October 2006. The strategy states that provision for disabled young people should challenge them and provide a sense of achievement, increase their personal autonomy and ensure they progress to new opportunities and experiences. The LSC will also set up the first 'national learners with disabilities panel' in 2007 to listen to learners and what they need. The DCSF, DH and DWP have published *Progression Through Partnership*, a joint strategy for shared funding and planning for disabled learners. For more information see www.dcsf.gov.uk

Effective practice

Improving Choice Pathfinder – LSC East of England Region

The Improving Choice Pathfinder was established to enable disabled young people aged 16–25 to access FE learning opportunities across the region. The project was set up in response to the lack of specialist provision in the area, which meant many disabled young people had to take up out-of-region placements rather than attending local colleges.

The Pathfinder is supported by £3.6 million of national LSC funds, which are being used to develop and implement support for disabled learners both in their learning experience and in providing collaborative support from different agencies.

In Suffolk, there is a three-pronged approach to Improving Choice, which seeks to address the development of provision, planning and support.

- Three transition brokers have been appointed (funded by the Suffolk Improving Choice Pathfinder) and are located in the three new Suffolk County Council Social Care Transition Teams. The brokers will be the point of entry for young people and will work with them through the schools to plan to meet needs and goals.
- A Development and Training Unit (DTU) has been established under the leadership of Sue Chesworth, head teacher at Belstead School. The DTU will look at issues of provision, and gaps in provision, and seek to upskill providers to meet young people's needs and ensure sustainability of the Pathfinder.

One of the key messages of the government's *Valuing People White Paper* is the need to increase the number of disabled people in employment.¹⁴ The benefits of work can be significant, giving people independence, choice, self-esteem and financial stability. At transition, it is therefore important that local authority professionals involved in the process understand the employment options available to young people and can signpost them to the sources of information, advice and guidance they require. They must also ensure that while still at school disabled young people have the opportunity and experiences to develop the skills employers need.

Higher education

Many disabled young people want to explore options to go on to higher education. This is very much still part of their transition to adulthood and the agencies offering support and advice, for example the Connexions service, need to ensure they can continue to support disabled young people in making choices and achieving their aims – up to their 25th birthday if needed. These aspirations need to start being raised from Year 9. For further information on duties and options in higher education for disabled students, visit the Skill website: www.skill.org.uk.

Further examples of effective practice are available from www.transitionfonetwork.org.uk.

Quality standards checklist

Quality standards Checklist A13 in Appendix 6 gives information on developing local choice and opportunities to support disabled young people.

14 *Valuing People: A new strategy for learning disability for the 21st century*, 2001, DH

Key legislation, guidance and resources

Disability Discrimination Act 1995 as amended by the **Special Educational Needs and Disability Act 2001** and the **Disability Discrimination Act 2005** and associated guidance

Part 4 of the DDA 1995 (as amended) sets out the responsibilities of schools, colleges, higher education institutions and local education authorities in relation to disabled pupils and students.

Learning and Skills Act 2000 – Sets out the LSC's and post-16 education providers' duties to provide sufficient and adequate quality provision for learners with learning difficulties

14–19 Implementation Plan, 2005, DfES from the *14–19 Education and Skills White Paper*, 2005, DfES

Revised Code of Practice for Providers of Post-16 Education and Related Services, 2007, Disability Rights Commission

A new deal for welfare: Empowering people to work, Green Paper, 2006, DWP. Sets out the government's plans for welfare reform, including the reform of incapacity benefit and the introduction of employment programmes to help people on benefits to find work

Further Education: Raising Skills, Improving Life Chances, 2006 outlines the role of the FE system including that for disabled learners, LSC

The needs of disabled students in further and higher education, 2006, information booklet, Skill: National Bureau for Students with Disabilities. www.skill.org.uk

Through Inclusion to Excellence, 2005, LSC. Reviews post-16 learning and skills provision for learners with learning difficulties and/or disabilities and makes recommendations for improving quality and choice

Transition to post-16 education, 2007 Skill: National Bureau for Students with Disabilities. www.skill.org.uk

The RITE transition: the only way forward, 2006, Dare Foundation and Ace Centre www.ace-centre.org.uk

Further information on legislation and guidance can be found in the resources pages at the back and in Appendices 1 and 2.

Person-centred approaches

*'Person-centred approaches are ways of commissioning, providing and organising services rooted in listening to what people want, to help them live in their communities as they choose.'*¹⁵

? Who

Disabled young people, families and friends, all professionals working with them

? Where

All services and locations where disabled young people can access support

15 *Planning with People: Towards person-centred approaches: guidance for implementation groups*, 2002, DH

Introduction

For the transition process to be truly person-centred, young people must have access to information that helps them understand what happens at transition, how to participate in the planning process, and how to make informed decisions about their future.

What are person-centred approaches?

There are a number of different tools used to carry out planning using person-centred approaches. Among others, these include Circles of Support, PATH (Planning Alternative Tomorrows with Hope), Essential Lifestyle Planning, Personal Futures Planning, and Personal Portfolios. Each of these methods are being used around the country to best meet the needs of disabled young people. Although the use of person-centred approaches are still relatively new, they share a set of principles, as set out below.

1 The person is at the centre

Person-centred approaches are rooted in the principles of shared power and self-determination. Built into the process of person-centred approaches are a number of specific features designed to shift the locus of power and control towards the person. Simple, practical examples of this are:

- as far as possible the person is consulted throughout the planning process
- the person chooses who to involve in the process
- the person chooses the setting and timing of meetings.

2 Family members and friends are partners in planning

Person-centred approaches take into account the context of a person's family and community. It is therefore not just the person themselves that we seek to share power with, but also their family, friends and other people from the community who the person has invited to become involved. Person-centred approaches start from the assumption that families want to make a positive contribution and have the best interests of the person at heart, even if they understand those best interests differently from other people.

3 The plan reflects what is important to the person (now or for the future), their capacities, and what support they require

In using person-centred approaches we seek to develop a better, shared understanding of the person and their situation. The planning process can be powerful – people's views change, new possibilities emerge, alliances are created, support is recruited, and energy is gathered and focused. The resulting person-centred plan will describe what is important to the person, their aspirations and the supports that they require.

4 The plan helps build the person's place in the community and helps the community to welcome them. It is not just about services; it reflects what is possible, not just what is available.

The focus of person-centred approaches are about getting a shared commitment to actions that have a bias towards inclusion. In this context,

services are only part of what people want and need; planning what services you need comes after planning what sort of a life you want.

5 The plan results in ongoing listening, learning and action. Putting the plan into action helps the person to achieve what they want out of life.

Person-centred approaches are not a one-off event. They are based on the assumption that people have futures, that their aspirations will change and grow with their experiences, and that the pattern of support and services that are agreed now will therefore not work forever. Person-centred approaches are a promise to people based on learning through shared action, about finding creative solutions rather than fitting people into boxes. They are about about problem-solving and working together over time to create change in the person's life, in the community and in organisations. To fulfil this promise, we need to reflect on successes and failures, try new things and learn from them and negotiate, and resolve conflict together.

Information above adapted from *Valuing People: A new strategy for learning disability for the 21st century: planning with people towards person-centred approaches: guidance for implementation groups*, 2002, DH, p14.

As use of person-centred approaches develops, many areas report difficulty in knowing how to make this system available for all young people who need it. Capacity to conduct the review process so all children and young people benefit – and a tangible improvement in outcomes can be demonstrated – is an area needing further thought and development for local authorities and their partners.

Effective practice

Using person-centred approaches in developing a transition plan with disabled young people and their families puts them at the centre of the process and can ensure they have control of the transition process. There is a range of emerging practice examples illustrating how using a person-centred approach at transition can not only benefit the disabled young person and their family, but also give professionals involved in the process a clear idea of what is needed to encourage and support the disabled young person to succeed.

Person-centred Transition Reviews

The Valuing People national team have developed a piece of work which brings a person-centred approach to year 9 reviews. In 2005–06 70 local authorities took part in training for staff in using this new approach. Over 140 young people received person-centred transition reviews. The aim of the work is to transform transition reviews by enabling disabled young people to think about what is important to them, what support they need and what is working and not working in their life. This can help local

authorities to carry out better transition planning by using their existing resources (that is: time, staff, money) in a person-centred way. For more information see www.valuingpeople.gov.uk

Bradford: Preparing for a person-centred transition review

The smooth running of a person-centred review depends on careful, if not meticulous, preparation. All parties need to know what they can expect from the meeting, and what is expected of them. Although the majority of practitioners agree with the principle of disabled young people participating in their reviews, many find it difficult to put that into practice. Practitioners in Bradford taking part in a project piloting person-centred transition reviews worked together to support the participation of a young man with complex communication impairments.

The head teacher arranged for a large room to be made available for the meeting. The class teacher organised for a range of favourite activities to be placed in the room – a video, computer and favourite programme, keyboard and box of building bricks. The independent facilitators met with the young man in school and at home. Having discovered he enjoyed looking at photos they gave him a disposable camera and asked if he would like to take photos of all the things he loved doing and all the people he loved being with. They asked his parents to support him in this activity.

As people arrived at the review, the young man was sitting at the keyboard looking at his photos. Throughout the meeting he kept picking up the photos. At one point when participants were talking about the things he liked doing, the young man picked up a photograph and pointed to a detail in the corner – a DVD. The facilitators added 'watching DVDs' to the list.

Prior to the review there had been concern that having a video, computer programme and keyboard in the room would be distracting. To everyone's surprise, rather than being a disturbance, the background noise added to the process in that the review undoubtedly belonged to the young man.

Further examples of effective practice are available from www.transitioninfonet.org.uk.

Quality standards checklist

Using person-centred approaches can greatly improve the levels of involvement disabled young people have in planning for their futures. Checklist A14 in Appendix 6 gives a short list of what developing a local strategy to implement this might include.

Key legislation, guidance and resources

Valuing People: A New Strategy for Learning Disability for the 21st Century, 2001, Department of Health, introduced an imperative for people working with disabled young people in transition to introduce person-centred approaches to the way they work. The White Paper outlines the need, 'as young people move into adulthood, to ensure continuity of care and support for the young person and their family; and to provide equality of opportunity in order to enable as many disabled young people as possible to participate in education, training or employment'. It identifies person-centred planning as being a tool to help this happen and states that services should use person-centred approaches to planning for everyone who needs services.

Person-centred Planning in Hampshire. A website about person-centred planning working in Hampshire www.pcp-in-hampshire.net

After School – What's Possible? Person-centred transition reviews, DVD 2007, Valuing People Support Team and Partners.
www.valuingpeople.gov.uk

My Future: Person-centred transition reviews for young disabled people, 2006, Project funded by the Yorkshire and Humberside Regional Partnership (www.thepartnership-yh.org.uk)

Further information on legislation and guidance can be found in the resources pages at the back and in Appendices 1 and 2.

Statutory services – an overview¹⁷

Introduction

Children's trust models and multi-agency working in the transition process

Education – schools in strategic planning

Social care services – strategy and structure

Adult social care?

Health services

Connexions, information, advice and guidance arrangements

Introduction

Disabled young people may need support from a number of agencies as they plan for and move towards adulthood. The support they require will depend on many factors, including their individual needs, local choices available to them and what they want to achieve. Many disabled young people will need support only from mainstream services, a smaller number of disabled young people need support from specialist services. For the most part, statutory agencies carry the responsibility for much of the support these disabled young people can expect to receive.

This chapter explores the statutory frameworks relevant to different services. It also looks at how each agency can work effectively with others to develop high-quality, responsive services for disabled young people. In particular, it sets out:

- the duties and responsibilities of each statutory service
- examples of effective practice on implementation of duties and innovative support for disabled young people and their families

Current developments

This guide has been produced at a time when many changes are taking place in the structure of health, education and social services. We have, where it makes sense, used the new terminology for services but made reference to some old terms, such as children's social care services, as we recognise many areas will remain in a state of transition to new models of working for some time to come. Regardless of titles, we have clearly outlined the duties, which will remain the responsibilities of these services.

Children's trust models and multi-agency working in the transition process

*'By 2008, local authorities are required to have in place arrangements that produce integrated working at all levels, from planning through to delivery, with a focus on improving outcomes. Local authorities may choose not to call this a 'children's trust', but the important point is that the way of working is in place and committed to.'*¹⁶

¹⁶ Every Child Matters: www.everychildmatters.gov.uk/aims/childrenstrusts/faq/

? **Who**

Disabled young people, families, directors of children's services, directors of adult services, primary care trust (PCT) leads for children's and adult services, disabled children's service managers, education officers (local authority), Connexions managers, lead members, managers of non-statutory agencies, professionals and practitioners in all services

? **Where**

Children and adult social services, councils, school forums, PCTs, acute and community health services, Connexions offices

The emergence of children's trust working models, co-located services, the participation of families and the promotion of joint working are all having a positive impact on the range of services available to support disabled young people, and are contributing to improved outcomes for individuals.

The setting up and effective functioning of a children's trust of some kind is integral to the success of local authority services and health agencies joining together to effectively plan and commission support for disabled young people at transition. *Every Child Matters: Change for Children* sets the context for the development of children's trusts:

'The Government's aim is for every child, whatever their background or their circumstances, to have the support they need to:

- *Be healthy*
- *Stay safe*
- *Enjoy and achieve*
- *Make a positive contribution*
- *Achieve economic well-being.*

This means that the organisations involved with providing services to children – from hospitals and schools, to police and voluntary groups – will be teaming up in new ways, sharing information and working together, to protect children and young people from harm and help them achieve what they want in life.¹⁷

The framework which supports these five outcomes will be added to shortly with examples of what the outcomes can mean specifically to disabled children. See www.everychildmatters.gov.uk for further details.

How a children's trust works

Local children's trust arrangements sit within the wider local authority planning and commissioning structure. Their specific focus is on bringing together services for children, young people and their families. The lead member and director of children's services share accountability and leadership of local children's trust arrangements. To reinforce this, broader governance and accountability arrangements are made with partner agencies.

The duty to cooperate set out in the Children Act 2004 is a duty for all children's trusts to promote cooperation with particular partners to improve the well-being of local children and young people. These partners are under

¹⁷ *Every Child Matters* (2005) Department for Education and Skills, www.everychildmatters.gov.uk/aims/

a reciprocal duty to cooperate. These key partners are:

- district council (in two-tier authorities)
- police authority
- Probation Board
- Youth Offending Team
- strategic health authority and primary care trust
- Connexions Partnership
- Learning and Skills Council (LSC).

In addition, there is a requirement to include in these reciprocal arrangements other agencies that work locally and which have an impact on services for children; for example, voluntary and community organisations, schools, GP surgeries and Jobcentre Plus.¹⁸ Partnership members also need to agree how disabled children and their parents will be involved in governance arrangements.

The Children and Young People's Strategic Partnership Board (CYPSPB) brings together chief executives of partner organisations involved in developing strategy in children's services. In many areas this group also serves as the children's trust board, or the children's trust board operates as a subgroup to the CYPSPB. The director of children's services usually leads on the work of the children's trust.

Local Authorities working through CYPSPBs have a duty to produce the local Children's and Young People's Plan (CYPP).¹⁹ This plan must set out how local authorities and partner agencies, such as health services, are going to support all local children. Local authorities are required to gather the views of children and young people to inform the plan. Although authorities awarded 'four stars' in the Audit Commission's comprehensive performance assessment²⁰ are not required to produce a plan, it is widely recognised as good practice to do so in any case. The plan can help to keep the needs of disabled children and young people on local agendas. Many areas have developed plans which set out their main aims, and alongside these have developed a set of supporting documents containing details of how they will achieve their aims. The development and operation of an authority-wide transition protocol should form part of these statements. See page 4 for more on developing a transition protocol.

Current developments – Regional support for the transition process

At a regional level, support is available from a number of agencies to develop effective processes at a local level. In some areas, Regional Partnerships support region-wide transition networks, which have proven effective in developing new approaches, successfully supporting disabled young people and their families, and improving services. Other support at regional level includes the Government Office Children's Service Advisors and the Regional Change Agents from the Care Services Improvement Partnership (CSIP), and the LSC has regional offices which oversee the work of local partnership teams. Further information on the work of these agencies is available from:

¹⁸ Statutory guidance on inter-agency co-operation to improve the wellbeing of children: children's trusts, 2005, DfES

¹⁹ Children Act 2004, section 17

²⁰ The Children and Young People's Plan (England) (Amendment) Regulations 2007
www.opsi.gov.uk/si/si2007/20070057

- Regional Partnerships www.teachernet.gov.uk/wholeschool/sen/regional
- Government Offices www.gos.gov.uk/national
- Care Services Improvement Partnership www.csip.org.uk
- Learning and Skills Council www.lsc.gov.uk.

Effective practice

A number of children's trusts have begun to improve communication between staff in different agencies and improve understanding of their different roles. They have done this through joint training, joint strategic planning and, in some areas, creating co-located teams. The introduction of integrated working processes, such as the Common Assessment Framework, lead professional role and information sharing are important features of a children's trust in practice. The strategic planning and commissioning process must be informed by the views of disabled young people and their families currently using, and professionals working in, local services. These views are essential for informing policy change and, ultimately, for identifying what constitutes effective service improvements. The following examples illustrate how two different local areas are addressing the complexities of bringing together a range of agencies, all with different priorities, budgets, targets and access criteria, to support disabled young people and their families at transition.

Sandwell: multi-agency co-located team

The children's trust has developed a co-located service whose role is to plan and facilitate services for disabled children and young people from birth to 25 years; none of the staff are employed directly by the children's trust. The staff team includes: learning disability nurses and psychologists from the Children and Adolescent Mental Health Service (CAMHS), a youth coordinator from the Youth Service, Connexions personal advisers (PAs), children's and adult social workers, sensory support teachers, preschool education and child development centre staff. The service's base hosts a range of direct provision, including outpatients clinics.

Support at transition is one of the team's key roles. The PAs identify young people from Year 9 reviews onwards who need a coordinated multi-agency response, then liaise with other staff in the team to ensure that respective responsibilities are agreed prior to a young person's 18th birthday. Young people requiring adult social care support will be allocated a social worker at age 16 who will stay with them until they are 25, thus improving the continuity of support.

Leicester City: Policy and Planning Officer – Transition

The LSC has funded this post, which is a resource for all partner agencies to encourage collaboration and inter-agency working practices to support transition activities. The post is hosted in Children and Young People's Services and reports to the Transitions Working Group, a subgroup of the Learning Disability Partnership Board (LDPB), and the CYPSPB.

The transitions action plan is closely aligned with other strategic and working plans, including the CYPP, Adult Learning Disabilities Plan, the LSC's priorities for disabled learners and the Connexions Service Business Plan. Some of the activities underway include:

- development of a transitions pathway plan
- person-centred review programme and introducing person-centred thinking skills to schools
- development of a CD-Rom 'Going to college', based on what young people say is important to them to meet their information needs
- best practice activities – information transfer, linked to the person-centred review activities
- proposals to develop a DVD for parents/carers focusing on their engagement in the transition process and the changes from children's to adult services.

Further examples of effective practice are available from www.transitioninfonetwork.org.uk.

Quality standards checklist

Approaching work with disabled young people in transition from a participative, multi-agency perspective can go a long way toward maximising outcomes. Checklist B1 in Appendix 6 gives a brief overview of issues to consider when looking at developing an effective multi-agency strategy for providing support at transition.

Checklist B2 in Appendix 6 lists the key issues to consider in ensuring the process of transition is on each agencies agenda and has a place in the local CYPP and the actions attached to it. Addressing change at this level provides foundations for developing operational strategy to support individual young people and their families when they need and on their terms.

Key legislation, guidance and resources

The children's trust arrangements have their foundations in the **Children Act 2004**. Although the Act does not set out a specific duty for local authorities to develop a children's trust, there is an expectation that authorities will use the duty to cooperate set out in the Act to develop a children's trust. The new integrated inspection processes also

concentrate on joint working and partnership arrangements, which are at the heart of children's trust models. Alongside this, the concept of children's trusts and joint commissioning is an integral part of a number of policy initiatives and pieces of legislation which affect the lives of disabled children as they go through the transition to adulthood. These include:

Education and Inspections Act 2006

Children's Workforce Strategy will have a significant impact on the future of joint teams and cross-agency working, including with extended schools, services and children's centres. See www.cwdcouncil.org.uk for more information.

Independent Living for disabled people is currently under review. The review is expected to report in autumn 2007 and make recommendations on support from: health; social care; transport; employment and housing. In addition to this review, the Disabled Persons (Independent Living) Bill is currently going through the parliamentary process. Further details on the review from www.dwp.gov.uk, and on the bill from <http://bills.ais.co.uk/>

Joint planning and commissioning framework for children, young people and maternity services: processes for joint planning and commissioning, 2006, DfES www.everychildmatters.gov.uk/strategy/planningandcommissioning

Pathways to success: A good practice guide for children's services in the development of services for disabled children, 2006, Evidence from the Pathfinder children's trusts, Council for Disabled Children www.everychildmatters.gov.uk/resources-and-practice/EP00128/.

Further information on legislation and guidance can be found in the resources pages at the back and in Appendices 1 and 2.

Education – schools in strategic planning

*'Education needs to become more 'transition-focused'. So programmes need to recognise and support the inherent messiness and unpredictability of the transition process as well as the fundamental educational needs of every young person during their transition ...'*²¹

? **Who**

Disabled young people, families, head teachers, special educational needs coordinators (SENCO), local authority SEN officers, educational psychologists, education welfare officer/education social workers, Connexions managers and personal advisers (PA), directors of children's services.

? **Where**

Secondary schools, all schools receiving local authority funding, extended services linked into schools, Connexions services, information and advice services.

²¹ *Improving transition planning for young people with special educational needs*, 2006, Lesley Dee, Open University Press

Introduction

Schools carry responsibility to coordinate the formal transition process and are well placed to bring together other key agencies and work with disabled young people to ensure their views are at the heart of the process.

The role of individual schools is changing. They are taking on responsibility for directly commissioning services, working in clusters and providing activities beyond the school day. They need to liaise with the children's trust, other schools and agencies to ensure the best use of local resources and to minimise duplication. Schools need to develop a clear strategy on transition support as part of this changing role with partner agencies.

It is in school, at Year 9, that the formal statutory transition process begins for children with a statement. This can be applied to other children the school thinks would benefit – for example, those on School Action or School Action Plus. This transition review process is covered in Chapter 1.

Strategic roles in school

Within schools, planning the transition to adulthood for all young people is part of the general school activity. Additional planning for disabled young people should be set within this wider context.

The roles and lead responsibilities at both local authority and school level are changing to reflect the new arrangements of children's services under the government's Every Child Matters (ECM) agenda. For more information see page www.everychildmatters.gov.uk.

In practice, the head teacher carries overall responsibility for implementing the transition process. This includes liaising with the local authority SEN officer and negotiating with partner agencies to ensure that disabled young people who will have a Year 9 review receive input from all relevant professionals and others who they would like to contribute. Timetables must be set to give enough preparation time for staff from other agencies and families. Often, the head teacher delegates most of this process to the school SENCO, who typically works with the Connexions service to plan the transition review. In many areas, the role of SENCO is being developed into that of 'Inclusion Coordinator', which carries a much broader remit. In practice this has developed in some schools into a role working with a range of children beyond those with SEN and includes consideration of social as well as educational support. For more information on this see www.dfes.gov.uk/standardsfund/grant202.htm and Becta's SENCO forum at <http://lists.becta.org.uk/pipermail/senco-forum>. The strategic and operational role of the Connexions service is also currently changing. Connexions services will come under the control of local authorities in 2008. Each area is currently negotiating what this will mean and how the new service will work to meet local need. For further information see www.connexions.gov.uk.

Effective practice

Hertfordshire is divided into four areas. Each of these has a transition planning forum. The forums meet termly and include special schools, FE colleges, schools, Adult Care Services, Children's services, Day opportunities and Connexions. They also include local voluntary groups and providers such as supported employment. The Connexions service has responsibility for feeding in the views of young people to these forums for each area. There is no funding attached to these forums, they take place on a good will basis. Each forum is chaired by the local College and Connexions is very much involved in contributing to setting the agenda.

Sandwell

Personal Advisers have been working with their schools to plan joint working with 'getting ready sheets' in school. In one special school teaching and support assistants are using the 'getting ready sheets' as a basis for individual discussions with pupils around their PSHE and future plans. The plans are recorded on the IT system and the personal adviser and any other professionals working with the young person are able to review the most recent planning sheets with them and save the most up to date version. The school have found this has assisted the young person greatly in communicating any concerns and expressing their ideas for the future.

Further examples of effective practice are available from www.transitioninfonet.org.uk.

Quality standards checklist

Checklists B3 and B4 in Appendix 6 set out the key issues to consider in successful strategic and multi-agency transition planning for disabled young people at Year 9.

Key legislation, guidance and resources

The key guidance document on provision of support at transition remains the **Education Act 1996**, and from it, the **SEN Code of Practice 2001**, which provides practical advice to local authorities, maintained schools and Connexions services carrying out their statutory duties to identify, assess and make provision for children's special educational needs.

The **Education (Special Educational Needs) (England) (Consolidation) Regulations 2001** SI 2001/3455 substantially amended by SI 2006/3346

Disability Discrimination Act 1995 as amended by the **Special Educational Needs and Disability Act 2001**

The **Disability Discrimination Act 2005** places further duties on schools, including developing a disability equality scheme (DES).

Education and Inspections Act 2006

The Learning and Skills Act 2000

Removing barriers to achievement: the government's strategy for SEN, 2004, DfES

Further information on legislation and guidance can be found in the resources pages at the back and in Appendices 1 and 2.

Social care services – strategy and structure

Children's social care

*'People say they want services that help them to realise their potential and make the most of their life chances. Services that offer them real choice about the care they use; flexible services that respect and fit with their lives; fair and non discriminatory services and the chance to have the same opportunities and to take the same risks as anyone else.'*²²

? Who

Disabled young people, families, team managers, social workers, transition social workers, directors of children's services, directors of adult services, transition champions (on the LDPB),²³ and occupational therapists

? Where

Children with disabilities teams, children's social care teams, looked after children teams, short break and family support services, multi-agency teams, specialist transition teams, LDPBs

Introduction

The way in which services are structured has been changing ever since the passing of the Children Act 2004 and the publication of the *Every Child Matters: Change for Children* agenda means local authorities are now required to appoint a director of children's services and director of adult social care services. These two posts share responsibility for transition planning.

At the time of writing, social care services and education are changing. These changes include:

- new staffing and commissioning structure
- new joint education and social care director
- imperatives to increase multi-agency working
- a new assessment framework
- a new information-sharing framework and system
- an inspection framework under further review.

This presents services with the opportunity to change the way in which they provide transition support. Reviewing provision with disabled young people and their families, collaborating with colleagues, developing a multi agency transition protocol, exploring sharing budgets and working with schools on commissioning can all lead to excellent support at transition for disabled young people. For further information on progress in these areas see www.everychildmatters.gov.uk.

²² *The state of social care in England 2005/06*, Dec 2006, Commission for Social Care Inspection (CSCI)

²³ *The Valuing People White Paper* (2001) requires every local authority to set up a Learning Disability Partnership Board (LDPB).

Eligibility criteria in social care

Unlike education and health, social care services use eligibility criteria to decide whether a disabled young person will receive a service. With limited budgets and capacity, some local authorities may adopt eligibility criteria. These criteria are used to establish how they might best meet their responsibilities under Section 17 of the Children Act 1989 for providing services to safeguard and promote the welfare of children in need in their area.²⁴

Disabled young people who are looked after by the local authority will have a care plan, (which is known as a pathway plan when they reach age 16 and are entitled to leaving care services).²⁵ This plan must be based on a thorough assessment of their needs and set out the full range of support services that will be required if they are to achieve their goals and aspirations into adulthood. Consultation and engagement with the young person concerned should be at the heart of this planning process. Partnership with other agencies is essential to enable disabled young people to benefit fully from the pathway planning process to spread resources to greatest effect.

In adult social care a community care assessment is used to determine which services should be provided. It is therefore common to find disabled young people losing ongoing support once they reach 16 or 18 (this differs across the country). Those who do make the transfer to one of the adult teams are often not offered the same levels or types of support they have received in the past. For example, access to a short break service may not be available from adult social care. Children's and adult services need to work closely together to offer the best support to disabled young people moving into adulthood. They need to ensure this support is ongoing, doesn't end abruptly, and meets the needs of the disabled young person.

Assessments at transition

The key agencies involved in the transition process should carry out joint assessments, using the Common Assessment Framework where appropriate. As use of the Common Assessment Framework and systems to support it develop locally, this will enable information to be shared easily and avoid the situation of disabled young people and their families having to repeat their stories several times. Where more than one agency is involved in providing support, agreement should be made on one person taking the role of lead professional.

For more information on the range of assessments potentially related to the transition process see Appendix 3, page 97. For more information on lead professionals see page 52.

Effective practice

As the structure of social care changes, many authorities are exploring new ways of working to improve services. Much of this work is built on principles of better communication within social care and the encouragement of multi-agency working.

²⁴ Whilst local authorities have responsibilities to assess need as a consequence of Section 17 there is no statutory requirement that they adopt 'eligibility criteria'.

²⁵ *Care Matters – Time for Change*, 2007, DfES. Proposals in this may change conditions for looked after children. See www.everychildmatters.gov.uk for further information.

A number of areas are developing some form of multi-agency transition team made up of children's and adult social care staff, therapists, Connexions staff, SENCOs and community nurses. Some areas have 'virtual' teams, who come together for joint training and planning, have a shared manager, and share information across each agency's systems. Other areas have developed integrated teams who may be located in the same office. These teams also work closely with colleagues from Community Adolescent Mental Health Services (CAMHS) teams and safeguarding children teams. Where transition teams have been set up, such as in Suffolk, Bristol and Sandwell, working patterns are changing, for example the number of assessments has been reduced substantially. This is in part due to professionals from different agencies agreeing which parts of their assessments they can share and working out appointments to carry out joint assessments.

Northamptonshire Transition and Liaison Team

The Transition and Liaison Team (TLT) is a new and unique team. It was established in November 2003 after it was noted that there was no service provision for young people with attention deficit hyperactivity disorder, Asperger's syndrome or Tourette's syndrome after they left school. The TLT started to see clients in February 2004.

The TLT is a county-wide service which provides detailed assessments, diagnoses and short-term focused interventions for young people aged 16+ with the following disorders:

- Asperger's syndrome
- Attention deficit hyperactivity disorder
- Tourette's syndrome.

The team also supports young people with the above disorders who are due to leave school and transfer into adult services and young people with a learning disability and mental health problems.

The TLT works with a range of services and agencies, including specialist forensic, learning disability, mental health (including inpatient), accommodation and commissioning, social care and health, employment, Connexions and further education services.

If not part of a transition team, social care practitioners supporting disabled young people and their families usually work within a specific team for children with disabilities. Which disabled young people receive a service from this team will depend on local eligibility criteria. This team will work closely with the children and families' main team and other family support services. In these 'children with disabilities' teams, new roles are being created which are specific to transition. A number of local authorities have developed 'transitions coordinator' or 'transition social worker' posts to carry a specific remit for prioritising the process of transition and supporting

disabled young people and their families through it. Primarily, this involves linking with partner agencies, following up agreed actions and negotiating joint assessments. The roles of transition coordinator and social worker are still developing and have different remits in different authorities. The following example shows how these roles are being used.

Nottingham City has developed the role of transition coordinator. In Nottingham transition coordinators will ensure the accurate maintenance of departmental systems for receiving referrals, monitoring progress, database information, etc as required. Team managers are responsible for allocating referrals and overseeing transition coordinators' workloads and, if necessary, creating waiting lists. Local practice may vary, but the essential component is close liaison between schools (usually SENCOs), Connexions personal advisers, childcare social workers and transition coordinators to ensure a well-planned and coordinated approach to each young person's transition. Good communication should ensure that all young disabled people are identified and that there is no duplication between agencies.

Further examples of effective practice are available from www.transitioninfonet.org.uk.

Key workers and lead professionals

Key workers and lead professional roles are increasingly being developed. These roles would be effective in any agency and for any professional involved with disabled young people they are supporting at transition. However, it is the case at the moment that social care is taking a lead in developing these roles to support disabled young people and their families at transition. These roles are covered in more detail on page 52.

Key legislation, guidance and resources

The **Children Act 1989** and the **Children Act 2004** underpin the work of children's social care services. For disabled young people and their families, the following additional legislation and guidance triggers a range of support:

Disabled Persons (Services, Consultation and Representation) Act 1986

NHS and Community Care Act 1990

Health and Social Care Act 2001

Carers (Equal Opportunities) Act 2004

Carers and Disabled Children Act 2000

Valuing People: A New Strategy for Learning Disability for the 21st Century, 2001, DH

Every Child Matters: Change for Children, 2004, DfES

National Service Framework for Children, Young People and Maternity Services, 2004, DH and DfES

Improving the Life Chances of Disabled People, 2005, Prime Minister's Strategy Unit, Cabinet Office

Lead professional guidance, 2006, DfES

In 2006 the DfES published *Future Positive – A Resource Guide for People Working with Disabled Care Leavers* to support them in the development of effective and joined up services. www.everychildmatters.gov.uk

Further information on legislation and guidance can be found in the resources pages at the back and in Appendices 1 and 2.

Adult social care

'We haven't got a social worker now. We did have one who came and sorted something out and then it got changed.'

Parent of a young person who has just turned 18²⁶

? **Who**

Disabled young people, families, directors of adult social services, social workers, transition social workers, transition coordinators, team managers, transition champions (LDPB)

? **Where**

Learning disability teams, physical disability teams, day centres, co-located teams, LDPBs, sensory teams, vulnerable adults teams, adult mental health teams

Introduction

Directors of adult social services have responsibility for overseeing the transition process for disabled young people. This means that adult and children's services need to work closely together to ensure that disabled young people experience a smooth transition either from children's to adult social care services or as new service users in adult care services. This is likely to mean a move into a specific team for physical, sensory or learning disability as adult social care is usually structured in this way.

Eligibility criteria in adult services

The eligibility criteria for the range of teams within adult social care services is different from those in children's social care. A community care assessment²⁷ is used to determine if a person over 18 is eligible for services. Adult community care assessments should lead to a care plan, similar to that in children's services, which will also have a multi disciplinary approach. For disabled young people this should be part of a longer-term process that offers support in making the transition to adulthood. If young people have received services, links with the disabled children's team should be strong

26 *Bridging the Divide at Transition: What happens for young people with learning difficulties and their families?* 2002, Heslop, Mallet, Simons and Ward, BILD, p71
27 NHS and Community Care Act 1990 B47

and information and data shared as a matter of course. This is particularly important when considering the local population and numbers of disabled young people likely to require a service from the adult team in years to come.

Effective practice

It is essential for children and adult social care services to work together and with partner agencies to ensure that disabled young people and their families get the support they need as they transfer across services. Many areas recognise the importance of starting this process early to make sure provision is set up in time through adult services, but also to allow disabled young people time to meet with new staff, express their wishes, and be at the heart of planning for their move to new services.

Adult social services teams may need to work with the leaving care team to transfer looked after children from children's to adult services. Most areas have a protocol in place agreed by staff across services to support this.

In **Coventry and Warwickshire** protocols are in place to ensure there is a co-ordinated approach between leaving care services and children's and adult social care teams for 'Looked After' young people during transition. These are cross-referenced in the local *Transition good practice guidelines for young people with statements of special educational needs*. This ensures that information is shared about the needs of identified young people from the age of 14 onwards. If a young person is 'Looked After' by Social Care Services, a Pathway Plan will also be completed. The protocol ensures that social workers from both the children's and adult team work closely with the young person, their parents/carers and all the agencies and professionals involved to ensure that there is a coordinated approach throughout their transition.

Further effective practice examples are available from www.transitioninfonynetwork.org.uk.

Quality standards checklists

Social care services' role in strategic planning and commissioning has changed to reflect new ways of working with partner agencies. This is particularly important at transition, when disabled young people experience a huge amount of personal change as well as changes in their support needs. Checklists B5 and B6 in Appendix 6 set out briefly the key issues to consider in transition planning in social care.

Key legislation, guidance and resources

Disabled Persons (Services, Consultation and Representation) Act 1986

NHS and Community Care Act 1990

Health and Social Care Act 2001

Our health, our care, our say: a new direction for community services, Health White Paper, 2006, Department of Health (DH)

Fair access to care services – guidance on eligibility criteria for adult social care, 2003, DH. Establishes the eligibility criteria for access to local adult services

Valuing People: A new strategy for learning disability for the 21st century, 2001, DH

Improving the Life Chances of Disabled People, 2005, Prime Minister's Strategy Unit, Cabinet Office

Guidance on the statutory chief officer post of the Director of Adult Social Services, 2006, DH

Best Practice Guidance on the role of the Director of Adult Social Services, 2006, DH

Further information on legislation and guidance can be found in the resources pages at the back and in Appendices 1 and 2.

Health services

*'I am currently attempting to transfer a 17 year old to adult services. I am very aware of the trauma of transferring from a cosy paediatric clinic to the busy elderly rheumatology outpatient department.'*²⁸

? Who

Designated medical officers, specialist medical consultants in children's and adult services, GPs, community children's nurses, learning disability nurses, school nurses, speech and language therapists, physiotherapists, occupational therapists, clinical psychologists, audiologists, PCT leads for children's and adult disability services, strategic health authority (SHA) leads, paediatricians

? Where

Clinics, hospitals, children's centres where health services are provided, GP surgeries, primary care trusts, acute trusts, multi-agency teams, schools, young people's homes, colleges and universities, CAMHS teams

Introduction

Maintaining good mental and physical health at this crucial time in growing up can greatly affect future life chances and a disabled young person's ability to participate fully in society. There is a great deal of evidence that young people who are 'lost' in the transition to adult health services are more likely to present later with avoidable and treatable complications of their conditions.²⁹

28 'Developing a programme of transitional care for adolescents with juvenile idiopathic arthritis: results of a postal survey', Shaw K L, Southwood T R, McDonagh J E, *Rheumatology* 2004;43 pp 211–9

29 *Transition: getting it right for young people. Improving the transition of young people with long term conditions from children's to adult health services*, 2006, DH

For many disabled young people and those with long-term complex health needs, having access to specialists and therapists may determine whether or not they can work or go on to further education.

Beyond the process of transition between health services, health professionals can offer support to disabled young people and their families in the wider school-led transition process. Providing assessments of need to contribute to the overall, multi-agency plan can be key in making sure disabled young people get access to the right support when they need it. This can include advice from speech and language therapists about ongoing communication needs, from physiotherapists on mobility and from occupational therapists on changing and likely future equipment needs.

At the time of writing, the NHS, along with social care and education services, is undergoing significant structural change which is having a direct impact on how services are delivered to disabled young people at transition. The SHA restructure, the future of children's services led in PCT's and the duty to cooperate brought in under the Children Act 2004, although challenging, do present an opportunity for a cultural shift in how the transition process is supported and how arrangements for the transfer to adult services is made. For further information on these changes see www.csip.org.uk.

Roles in health services

The process of transition planning to adult health care often starts at different ages depending on the disabled young person's condition. For example, the Royal College of Nursing (RCN) guidelines³⁰ state planning should begin at age 13, while the rheumatology evidence-based programme (see Birmingham example below) states that this process should begin at age 11. The entire team of health professionals working with disabled young people needs to incorporate transition planning into standard appointments and discussions with all disabled young people they are working with. The RCN guidelines set out below provide a useful overview of the transition process from paediatric to adult health care.

Health care plans

Early stage (12 to 14 years)

Aim to introduce the young person and their family to the concept of transition to adult health care, and to the need for the young person to develop their autonomy at the same time as being supported by their family. The young person should become aware of their own health and care needs, and the full implications of their medical condition. An assessment of the young person's level of understanding is as important as providing information and education about the services available. The concept of seeing a professional on their own should be gradually introduced to the young person in order to give them and their family time to adjust to this change.

30 Adolescent Transition Care, Guidance for Nursing Staff, 2004, Royal College of Nursing

Middle stage (14 to 15 years)

Aim to give the young person and their family an understanding of the transition process and of what they can expect from the adult health care system. The young person should practice their skills, gather more information and begin to set goals for participating in their own care.

Late stage (15 to 16 years)

By now, the young person and their family should be feeling confident about leaving the paediatric system, and the young person should have a considerable degree of autonomy over their own care.

The ages indicated above are for general guidance. The young person should be encouraged to take the lead on the speed of progression with support from their key worker. It would be helpful if the young person was able to make contact with the adult services they will eventually move to and be supported to do so. Transition will proceed at different rates for each young person.³¹

Role of GPs

GPs are an initial point of access to all primary health services. For many disabled young people, contact with their GP is minimal and most contact is with their paediatrician. The change to adult health services often involves multiple specialists rather than one person overseeing their medical needs. Each of these specialist teams and consultants will need time to establish a relationship with the young person and each may require an assessment to be carried out. The GP or school doctor needs to be involved in the transition planning process, as they become the first point of contact for young people on leaving school for any therapies which may have been provided via the school. Where there are continuing needs and an adult service exists, involved health professionals, including therapists, can refer on directly, however the GP needs to be kept informed as the ongoing medical link.

Effective practice

Health Plans

The drawing up of a Health Action Plan can make sure disabled young people continue to have access to services they need to stay healthy and not 'fall between' services. In some areas, health action plans are developed from the Year 9 transition review. Like the wider transition review, the compilation of a health action plan, (HAP) is a process rather than a one off event. It can take some months to bring together all the necessary information from a range of health professionals to ensure all aspects of a young person's particular health support needs are covered. Working with other agencies in the lead up to a review and using existing appointments with the young person and their families to discuss what the plan should contain can help speed up this process. For more information on Health Action Plans see Appendix 4.

31 Adolescent Transition Care, Guidance for Nursing Staff, 2004, Royal College of Nursing. See Appendix 4 for example pathway.

Leeds Young Adults Team

Since 1988 the Leeds Young Adults Team (YAT) has provided support and practical help to physically disabled young people aged between 16 and 25 to help them achieve the lifestyle they want. The team is made up of physiotherapists, doctors and staff from clinical psychology, occupational therapy, family planning, speech and language therapy, and social work teams. Research into the effectiveness of the service found that, 'Young disabled people given YAT services were 2.5 times more likely to participate in a range of activities than those given ad hoc support services – and cost-effectiveness analysis showed no difference between these two forms of support.'³²

For more information about the Leeds Young Adults Team go to www.leedsyat.nhs.uk.

Protocols

Some areas have developed clear, effective protocols to support disabled young people in their transition to using adult health services.

Birmingham

In Birmingham transfer of young people with arthritis from the paediatric to the adolescent clinic is flexible, depending on the patient and their illness, but usually occurs at 13–14 years. A further transfer to adult care occurs from age 16–18 years to the adult rheumatologist. Dedicated older adolescent/young adult rheumatology clinics have been developed at the City Hospital and Selly Oak Hospital which will facilitate shared care in late adolescence.

The rheumatology team will consider the key elements that have been identified for an effective transition programme and will ensure they are incorporated into their departmental policies, business case planning and discussions with commissioners. The needs of parent(s)/guardians during transition will also be acknowledged and addressed. It should be noted that rheumatology services tend to be quite different from more general services, many of which would not have the resources for this type of support.

The transitional programme starts at age 11 and was developed following an extensive needs assessment. Resources and tools used in this programme are available on the team website www.dreamteam-uk.org.

See Appendix 4 for example of a health transition pathway.

Further examples of effective practice are available from www.transitioninfonynetwork.org.uk.

Quality standards checklists

Checklists B7, B8 and B9 in Appendix 6 highlight key activity in developing effective service transfer.

32 Bent N, Tennant A, Swift T, Posnett J, Scuffham P, Chamberlain M, 'Team approach versus ad hoc health services for young people with physical disabilities: a retrospective cohort study', *The Lancet*, Volume 360, Issue 9342, pp 1280–6, N Bent, A Tennant, T Swift, J Posnett, P Scuffham, M Chamberlain

Key legislation, guidance and resources

Health and Social Care Act 2001

NHS Act 2006

Education Act 1996

Special Educational Needs Code of Practice, 2001, DfES

Valuing People: A new strategy for learning disability for the 21st century, 2001, DH

National Service Framework for Children, Young People and Maternity Services, 2004, DH and DfES

Our health, our care, our say: a new direction for community services, Health White Paper, 2006, DH

Integrated multi agency transitional care pathway for young people with life threatening and life limiting conditions, 2007, Association for Children's Palliative Care www.act.org.uk

Adolescent transition care: guidance for nursing staff, 2004, www.rcn.org.uk

Bridging the Gaps: Health Care for Adolescents, 2003, Royal College of Paediatrics and Child Health, www.rcpch.ac.uk

Transition: getting it right for young people. Improving the transition of young people with long term conditions from children's to adult health services, 2006, DH and DfES, www.dh.gov.uk/transition

Additional practical health guidance is currently being produced by the DH. The guide will be published in Autumn 2007. Information about the guide will be posted on the CSIP website: www.csip.org.uk and on www.transitioninfonet.org.uk

Further information on legislation and guidance can be found in the resources pages at the back and in Appendices 1 and 2.

Connexions, information advice and guidance professionals

*'The quality standards will cover the full range of issues on which young people might seek IAG, not just careers and learning. They will cover services for 11–19 year olds, and young people with learning difficulties and disabilities up to their 25th birthday. We will be consulting widely during their development.'*³³

? Who

Disabled young people, families, Connexions personal advisers (PAs), careers advisers, Jobcentre Plus staff, information, advice and guidance (IAG) workers

? Where

Connexions one-stop shops, schools, Jobcentre Plus, colleges, universities, local authorities

33 *Youth Matters, Next Steps*, 2006, DfES.
Proposals on future IAG provision.

Introduction

Careers and guidance professionals are at the heart of the ongoing transition process for all disabled young people. They provide impartial information, advice, guidance and support until the young person's 25th birthday if need be. By working alongside a disabled young person they can provide invaluable support and information on options for education, training and employment opportunities.

Current developments

The current arrangements for the provision of information, advice and guidance (IAG) for all young people is changing.³⁴ The DfES Green Paper *Youth Matters* set out the government's plans for the future of IAG. *Youth Matters, Next Steps, 2006*, and the *Quality Standards for Young People's Information, Advice and Guidance* consultation document (2006, DfES) confirms how it proposes to take these plans forward. This includes:

- responsibility for IAG and the funding that goes with it will pass from Connexions to local authorities through children's trusts, schools and colleges from April 2008
- schools and colleges will have the right to commission IAG directly from local providers, including existing Connexions services.

The DCSF is currently putting in place measures to ensure that assessments that are compliant with S140 of the Learning and Skills Act 2000 continue under the new arrangements in local authorities. Further information about this can be found on the DCSF's website:

www.dcsf.gov.uk.

³⁴ We have used the term Connexions and Connexions PA throughout the document to cover current arrangements and indicate what the role of other IAG providers may be in future. For further information see www.connexions.gov.uk

³⁵ Special Educational Needs Code of Practice, 2001, DfES

³⁶ Under Section 140 of the Learning and Skills Act 2000 the Secretary of State is responsible in law for these assessments. The Department has made arrangements whereby Connexions carries out the assessments for the Secretary of State.

The role of Connexions personal advisers

Connexions PAs provide information advice guidance and other support to enable young people to deal with a wide range of issues as they make the transition to adulthood.

A Connexions representative, usually the PA, must attend the Year 9 review for young people with statements and has a role in overseeing the transition process following that meeting.³⁵ The PA should contact the young person well in advance of the formal review meeting to make sure they have time to get to know the young person and support them to think about what will be important to them in the future, and ensure they understand how transition planning will help them achieve their goals.

The Connexions Service is responsible for arranging assessments for all young people with SEN statements who are in their last year of compulsory schooling. For most, but not all, this will be to plan going into further education or training.³⁶ Connexions should also offer assessments to young people without statements, for example those on School Action or School Action Plus in their final year at school. This assessment will primarily focus on the educational and training needs and the provision required to meet them and this report should help the LSC and post-16 provider plan to meet

their needs. Under S13 of the Learning and Skills Act 2000 the LSC is required to have regard to S140 assessment reports in discharging its functions.

In preparing for these meetings there is an expectation that the PA will work with individual young people to look at their priorities and views and how these will be conveyed at the meeting.

Effective practice

Connexions PAs have a key role in bringing together the various assessment processes the young person is likely to have undergone and ensuring that the information needed to support them is recorded. This should involve working closely with the school, social services and some health services.

Existing Connexions services and any new IAG providers will use a range of assessment tools. This will have regard to the developing Common Assessment Framework, the existing Connexions APIR framework and further developing practice in this area.

Somerset

In Somerset, a partnership between Connexions Somerset, social services and health has improved transition for young people with learning difficulties.

Taking the lead from the *Valuing People* White Paper, which highlighted the importance of effective transition from children's to adult services for young people with learning difficulties, the Somerset LDPB agreed to joint fund with Connexions Somerset four PA posts to work with young people in transition. In addition to the four PAs working with young people with learning difficulties, social services and Connexions fund a half-time post to work with young people with physical and sensory impairments.

Transition personal advisers (TPAs) are employed by Connexions and work closely with Connexions and social services. Their job involves working with disabled young people who are likely to need long-term social services provision. TPAs commence work with young people when they reach 16. They work in conjunction with the school-based Connexions PA from the time of the Year 9 transition review – and will continue to work with a young person until they make an appropriate transition.

TPAs work with young people and their families to explore a range of opportunities and so expand choices, beyond day services and residential provision. Education, employment, health, leisure and housing are all considered in this holistic approach.

To ensure that the young person's plans are person-centred and fit within the Common Assessment Framework, Connexions Somerset has developed a workbook using 'total communication', which

links into the development of the community care assessment.

This joint approach to transition ensures that social services become aware of the needs of future services users several years in advance, enabling them to plan. The young people and their families have a consistent dedicated worker to support them through the transition period.

This work has been highlighted as good practice by the Social Services Inspectorate and the Valuing People Team. It also contributed to the successful inspection of Connexions Somerset.

Further examples of effective practice are available from www.transitioninfonynetwork.org.uk.

Quality standards checklists

The provision of independent, high-quality and timely information, advice and guidance is essential for disabled young people and their families at transition. Changes to the way this is provided are in progress. Whatever the new system looks like, Checklists B10 and B11 in Appendix 6 outline how Connexions and IAG arrangements can support disabled young people.

Key legislation, guidance and resources

Education Act 1996

Learning and Skills Act 2000

Section 140 of the Learning and Skills Act 2000, 2004, Revised Guidance,
Connexions Service National Unit, DfES

Special Educational Needs Code of Practice, 2001, DfES

Improving the Life Chances of Disabled People, 2005, Prime Minister's
Strategy Unit, Cabinet Office

Removing barriers to achievement: the government's strategy for SEN, 2004,
DfES

Youth Matters, 2005, Youth Matters, Next Steps, 2006, DfES

Quality Standards for Young People's Information, Advice and Guidance
(IAG) A consultation, 2006, DfES

Developing Connexions: Young people with disabilities, mental health needs or
autism, 2004, Nic Rowland-Crosby, Foundation for People with Learning
Disabilities

Further information on legislation and guidance can be found in the resources pages at the back and in Appendices 1 and 2.

Participation and further support

Participation of disabled young people in the transition process

Participation of families in the transition process

Supporting disabled young people and their families: key workers and lead professionals

Supporting disabled young people and their families: direct payments and individual budgets

Information for disabled young people and their families about the transition process

Leisure services and activities

Youth services

Housing

Transport

Participation of disabled young people in the transition process

*'The views and aspirations of the people who use services are not yet at the heart of commissioning services for individuals. Councils need to pay more attention to what people say about the qualities that are important to them in services.'*³⁷

? Who

Disabled young people, parents and carers, all professionals working with disabled young people and their families, including social workers, advocates, teachers, youth workers, GPs, health service staff and Connexions personal advisers, local employers

? Where

All services and agencies that young people are in contact with, including local advocacy services, social care and education, health services, Connexions, local leisure services and extended school activities

Introduction

Disabled young people have the right to participate and be at the centre of the decision making process about their lives and be fully involved in actions and agreements which affect them. The use of person-centred approaches to achieve this are covered in Chapter 1. The following pages examine the wider issues around participation which have an impact on disabled young people in the transition process.

Local community activity – participation in local planning

Many mechanisms for young people's involvement exclude disabled children, mainly unintentionally. For example, local youth parliaments or forums are the main groups that report to local Children and Young People's Strategic Partnership Boards and children's trusts boards. Children and young people cite the following reasons for not participating in these parliaments and forums:³⁸

- feeling those elected do not represent them
- lack of transport to and from the meetings
- discussions are about things that don't interest them
- no senior professional takes the group seriously.

These issues are particularly pertinent for disabled children and are compounded by:

³⁷ *The state of social care in England 2004–05: A summary*, p21, Commission for Social Care Inspection (CSCI), December 2005

³⁸ *Views from young people working with youth services*, 2005, Council for Disabled Children (CDC) unpublished

- lack of time or support to communicate (non-verbal)
- no easy-to-read or accessible information is available.

This means that the views of disabled young people are often not represented within these structures. Local authorities and partner agencies need to give further consideration to promoting the participation of all children and young people.

Individual support to participate – advocacy

‘For disabled young people with needs such as significant cognitive or communication impairments, the role of an advocate can be really important as the transition [to adulthood] can often mean change away from those who know the young person and having to face unfamiliar people all at once.’³⁹

It is important for disabled young people to have a voice that is separate from that of their family. Advocacy support can often provide them with the help they need to independently communicate their thoughts and aspirations throughout and make the transition process less daunting.

Effective practice

A number of areas have set up specific projects to help disabled young people to participate more fully in local community activity and specifically, in their transition planning. Advocacy services are used to support this work in a number of areas.

Sunderland: City Equals

Sunderland Youth Development Group is committed to working with disabled young people to ensure they can be actively involved in decisions that affect them. City Equals is a group of young disabled people who advocate for other young people, enabling their voices to be heard, understood and responded to within the wider community, by linking into Sunderland Youth Parliament, which in turn informs the Council’s work. All the young people in the group are going through the transition process and much of the work they do helps them think about growing up and next steps. The group are also regularly asked by the council to be involved in consultations about new services.

Cambridge: Young People Speaking Up (YPSU)

This service runs projects, campaigns and courses with 11–25 year olds making the transition from school to college or work. Disabled young people are supported to explore their aspirations and the options available to them, and then make some of those aspirations a reality. These aspirations and options are also fed

³⁹ ‘Moving into adulthood: Young disabled people moving into adulthood’, *Foundations*, Ref 512, Joseph Rowntree Foundation, June 2002

into transition reviews, to ensure that the young people's voices are heard at the statutory planning stages for their futures.

YPSU provides representation in two ways;

- One-to-one advocacy service provides an independent ear for young people or support to speak up about something important to them.
- Consultation service enables young people to represent their peers direct to service providers such as Connexions, social services, etc.

Contact YPSU at www.speakingup.org

Quality standards

There is a wealth of information and resources on planning and promoting the participation of disabled young people. See the key resources list below and the Resources section on page 71.

Key legislation, guidance and resources

The Children Act 2004. Sets out the need for services to ascertain, so far as is reasonably practicable and consistent with the child's welfare, the wishes and feelings of a 'child in need'. It also creates the post of Children's Commissioner for England.

Disability Discrimination Act 2005. Brings in new duties to promote the equality of disabled people and their participation in local decision making and for public bodies to provide evidence of this and other actions.

Education Act 1996. Special Educational Needs Code of Practice, 2001, and the Education Act 2002 also uphold the principles of participation.

Involving Children and Young People in Meetings and Reviews, 2006, Yorkshire and Humber Regional Partnership and Barnardos. Guidance pack produced by Yorkshire and Humberside Partnership with Barnardos, which includes guiding principles for professionals, promises to children, good practice examples and links to further information: www.thepartnership-yh.org.uk

Participation Resources list. Regularly updated list of organisations and resources concerned with the participation of disabled children and young people. Council for Disabled Children. Available online from www.ncb.org.uk/cdc

Further information on legislation and guidance can be found in the resources pages at the back and in Appendices 1 and 2.

Participation of families in the transition process

*'The success of initiatives to involve users and carers should be judged not by how many people take part but by the amount of change that takes place in the services people receive and the quality of their lives.'*⁴⁰

? **Who**

Disabled young people, families, all professionals working with disabled young people and their families with responsibility to support their full participation in planning for their futures

? **Where**

All services and agencies in contact with disabled young people and their families

Introduction

For disabled young people, their parents⁴¹ are often at the heart of brokering support services and communicating their needs to a range of agencies. They often act in a 'key worker' type role and are the main support to their children. Their views and full participation therefore are essential during transition. Although it is important to engage with disabled young people separately from their parents when seeking their views and wishes, parents, siblings and other significant people need to be at the heart of the planning process.

Supporting participation

In order to participate at all levels, parents require information before meetings, access to information on local resources and support from identified professionals.

A number of local authorities have parent representatives attending the local children's trust board and a greater number have some kind of sub group of parents' representatives for families with disabled children which feeds into local strategic planning. Participation at this level improves services and ensures parents feel empowered, it also helps relationships between professionals and parents, as time spent together helps professionals understand the pressures that are on parents, and similarly helps parents to understand the constraints that are placed on professionals. They often find they make strong partners to campaign for change.

All local authorities have a legal duty to provide information, advice and support to parents of children with special educational needs (SEN).⁴² This provision should be at 'arms length' from the local authority so that parents are assured that the advice and information they receive is impartial, and that the people they receive it from are independent of any decision-making processes; Parent Partnership Services are the local organisations which deliver this. Some Parent Partnership Services are based in the voluntary sector but most remain within the local authority. Most services offer access to Independent Parental Supporters (IPs) who are volunteers trained to

40 Joseph Rowntree Foundation, Social Care Summary 3, 1995

41 We use the term 'parents' here to mean parents and carers.

42 S332A Education Act 1996.

provide support to parents. Parent Partnership Services can provide a range of support and advice to families going through the transition process, including:

- running a confidential helpline
- giving impartial information and advice around SEN issues
- offering support in preparing for and attending meetings
- helping to fill in forms and write letters/reports
- supporting parents/carers in resolving disagreements with school or local authority
- signposting to other statutory and voluntary services
- linking to local parent support groups and forums
- ensuring that parents'/carers' views help inform and influence local policy and practice
- offering training opportunities for parents and professionals.

Further information on how Parent Partnerships can support families can be found on the National Parent Partnership Network website www.parentpartnership.org.uk.

Effective practice

In **Surrey**, reviews are often run by the Parent Partnership Services in a person-centred way. The Parent Partnership Service provides support and advice to parents throughout the transition process and the transition review is often run by them. Parent Partnership workers support and accompany the family.

Sutton parents' council

In the London Borough of Sutton parents have been involved in the development of the children's trust since an initial consultation exercise in 2001. This fed into the Joint Strategy, which later became the foundation for Sutton's application for Pathfinder trust status.

A Parents' Forum meets regularly, giving parents an opportunity to discuss service provision and decide what they would like to raise at Trust board level.

The Trust has six parent representatives on the board. This gives parents parity with the statutory and voluntary sectors, which also have six representatives. This model has increased the direct communication between parents and senior decision-makers within each of the main services. Additionally, relevant officers within the borough attend regularly to report to the board and hear directly from parents. Parent representatives also sit on Trust subgroups for a wide variety of relevant services. This enables them to have a voice at other levels and to work directly with a wider range of professionals.

The Trust funds a Contact a Family worker who organises the election and training of the parent representatives and facilitates the running of the Parents' Forum.

As a result of this level of participation by parents, there have been some significant changes in service provision. These include the promotion of a key worker service for parents/carers, the development of an inclusive summer youth scheme, and a project to develop information and support resources for parents/carers and the professionals who work alongside them.

Further examples of effective practice are available from www.transitioninfonet.org.uk.

Quality standards checklist

It is important that parents feel listened to and have enough support to fully participate at a local strategic and operational level. The transition review Checklists B7 and B11 in Appendix 6 contain useful action points on preparing meetings with parent and other family participation in mind. A range of further comprehensive information is available in the publications below and the Resources section on page 71.

Key legislation, guidance and resources

Disability Discrimination Act 2005. Brings in new duties to promote the equality of disabled people and their participation in local decision making and for public bodies to provide evidence of this and other actions.

Carers (Equal Opportunities) Act 2004. Rights to assessments for carers and highlighted need for support, for example to access further learning.

NHS Act 2006. Places a duty on health agencies to consult on service planning and development with service users.

Parent Participation – improving services for disabled children and their families parents pack/professionals pack, 2004, Contact a Family and Council for Disabled Children www.cafamily.org.uk/packs

Further information on legislation and guidance can be found in the resources pages at the back and in Appendices 1 and 2.

Supporting disabled young people and their families: key workers and lead professionals

'Whatever the title of the role, the critical point is that children, young people and their parents or carers have access to one practitioner who acts as a single point of contact for them, who supports them in making choices

*about the help that they need, who ensures that they receive the right help at the right time, delivered by the most appropriate practitioners, and who makes sure that professional duplication and inconsistency are avoided.*⁴³

Introduction

Disabled young people and their families are often required to work with a range of services to get appointments, follow up actions and find out when meetings are planned and who is taking forward decisions. Many families welcome the opportunity of having a key worker or lead professional to take on a supporting role to help them with these tasks.

Responsibilities of the roles

Lead professional

The role of lead professional is to work primarily with families who have some identified need but do not meet the eligibility criteria for specialist services and support. The Lead Professionals guidance states:

'Where [the young person's needs] require input from a range of professionals outside the school setting or a high degree of family support is required, it may be appropriate for someone else [other than the SENCO] to take on the lead role. During Year 9, for pupils with statements, the personal adviser (Connexions) takes on responsibility for overseeing the delivery of the transition plan and is likely to be the lead professional.'

The guidance also states: *'Where the child or family have a key worker, they are the lead professional.'*⁴⁴

At the time of writing, some areas are piloting a scheme where lead professionals are given a small budget for each young person with whom they work. One area is focusing specifically on disabled young people and their families. For more information see www.everychildmatters.gov.uk.

Key worker

The key worker model has been successfully applied in early years settings and is increasingly being used to support young people aged 14–25. Key working, in the context of supporting families with disabled children, is usually used to refer to a person acting as a single point of contact for a family. This person has an advocacy and support role. They usually work with families who have children with complex needs over an extended period of time. The role is likely to be much more involved than that of lead professional.

Effective practice

In developing these roles, many areas have found that identifying children with specific needs, beginning work with a small group of families, and working with a specific age group provides a reasonable starting point to build an effective service.

43 Page 34, *Lead Professional Guidance for children with additional needs*, 2005, DfES

44 *Lead Professional Guidance for children with additional needs*, 2005, DfES

Wiltshire's Transitions Strategy includes a statement about the use of lead professionals:

Aim Provide a lead professional as a named contact to link services together for service users, parents and carers

Action Lead professional ensures parents, carers and service users understand and are prepared for transitions process. Parents and carers are informed of lead professional and role of agencies during transition in Year 8.

Lead professionals are identified for all service users to link services together. Lead professional allocated in Year 9 and oversees the implementation of the transitions plan.

Quality standards

See Checklist C1 in Appendix 6 for quality standards around key workers and lead professionals.

Key legislation, guidance and resources

The role of lead professional is identified in the **Children Act 2004** as a key element in ensuring that frontline services provide integrated delivery for families.

The Care Coordination Network UK produced a set of standards for key workers in 2004. This can be found at www.ccnuuk.org.uk

Information on how key worker and lead professional roles are developing can be found at www.everychildmatters.gov.uk

Further information on legislation and guidance can be found in the resources pages at the back and in Appendices 1 and 2.

Supporting disabled young people and their families: direct payments and individual budgets

*'Individual budget pilots are already demonstrating that some people are looking for very different services to those traditionally commissioned by councils.'*⁴⁵



Who

Disabled young people, families, children's social workers, family support workers, personal assistants, all service providers



Where

children's services departments, family support services, leisure services, local support agencies

45 *The state of social care in England 2005–06: Executive summary*, CSCI, December 2006

Introduction

Direct Payments and individual budgets represent a shift in thinking about support. Both are alternatives to direct service provision from local authorities and are about shifting the balance of choice and control to service users and away from service providers.

Access to direct payments and individual budgets

Direct payments become an option once families have received an assessment from children's services. It is important to remember that Direct Payments do not change eligibility criteria or assessment processes. However, if an assessment identifies needs for the young person or carer in families, which might have been provided by direct service provision the family and young person must be offered the choice of direct payments as an alternative.⁴⁶ Families can choose to have all of their identified needs met through Direct Payments, some of them or none of them. Direct payments are paid to parents of disabled children up to the age of 18. At 16 and 17 disabled young people can choose to have them in their own right. In some areas protocols have been worked out to help ensure a smooth transition to adult services that enable young people to employ the same personal assistant when moving into adult services.

Building on the learning from direct payments, a small number of local authorities are piloting Individual Budgets in children's services. The Department of Health publication 'Our health, our care, our say: a new direction for community services', published in 2006, sets out plans to pilot individual budgets. An Individual Budget is designed to provide individuals who currently receive services with a greater choice and control over their support arrangements. The government is committed to piloting individual budgets with a view to rolling them out nationally should they prove successful. A further decision on whether to develop a wider pilot programme for young people under 18 is currently awaited. See www.everychildmatters.gov.uk for updates on this work.

Effective practice

Devon In-House Direct Payments service

Devon is divided into five areas, each area has a Children's Direct Payments worker.

Once a Keyworker has spoken to a family and an assessment of need has been carried out by the Children and Young People's team, and if the family are interested, the Direct Payments worker talks to family and explains how direct payments works. This will include detail about aspects of direct payments such as what the money can be spent on and how to employ someone.

In Devon it works well having dedicated posts in the children's team. The workers have a good understanding of families' needs.

Workers meet regularly to share learning, ideas, and information. The five posts in Devon are overseen by the Direct Payments County Coordinator. The workers also attend the South West Network's Children's Direct Payments group to share ideas and effective practice across the region.

There are over 300 families receiving direct payments in Devon. Families need varying levels of support at the beginning – some need minimum support to set the direct payment up (up to six hours) while other families need fairly intensive support and may need up to 30 hours of worker's time to get everything in place. It has been noted that direct payments tend to be more successful when support is made available to families in the early days of setting up.

A quarterly newsletter is sent to all families; this is a way of keeping them informed and up to date with issues such as employment around holidays, sick pay and so on.

Individual Budgets

Aaron is a young man who at 14 years old was facing significant challenges. He had a difficult relationship with his family and his placement at home was in doubt. Planning meetings about Aaron's next steps and how to involve the growing number of professionals were set up. Aaron was supported to participate in these meetings.

The idea of individual budgets as a way of supporting Aaron was suggested. Some of the first things that had to be overcome were worries from Aaron's mum and the professionals who worked with him about how the budget would work.

Aaron had access to an advocate to help him think about what was important to him. Person-centred approaches were also used to help Aaron and people working with him think about what is important to him, what he enjoys doing, and who is important to him.

Aaron identified a range of things including; 'I want a home of my own and live with people who love me.'

Aaron is now living in his own flat in YMCA supported accommodation. His supporter lives in the flat next to him to provide 24 hour support if he needs it. He has an individual budget that funds his support, which has all been set out in an agreed Support Plan. Aaron is making friends with other young people in the accommodation. He is learning to use the bus so he can travel independently. Aaron has recently started chairing his own support meetings, which he is really good at.

Things to keep an eye on:

- Ensuring money is paid in a timely manner
- Ensuring that there is appropriate Risk Management
- Keeping professionals motivated and interested
- Remaining Outcome Focused – thinking about what Aaron wants
- Managing competing outcomes

Aaron is a very happy young man.

This article was first printed in the Transition Information Network's magazine *my future choices*. See www.transitioninforonetwork.org.uk.

Quality standards checklists

The use of direct payments and individual budgets can bring a new dimension to service planning and delivery. As use of these methods of support evolve it is important for local authorities and partner agencies to be aware of developments and duties. Checklists C2 and C3 in Appendix 6 offer some basic information.

Key legislation, guidance and resources

Carers and Disabled Children Act 2000. Extended power to award direct payments to groups including: disabled young people aged 16 and 17, parents of disabled children.

Health and Social Care Act 2001. Altered previous legislation by making issue of Direct Payments a duty, instead of providing direct services. This came into force April 2003. Extended the provision of direct payments and repealed the previous legislation.

Department of Health individual budget pilot programme.

<http://individualbudgets.csip.org.uk>

Further information on legislation and guidance can be found in the resources pages at the back and in Appendices 1 and 2.

Information for disabled young people and their families about the transition process

'They are all saying stuff in their own language which you don't really understand no matter how many times they repeat it. They are saying things that seem to require you to make a decision but you don't know what your options are because nobody can explain it to you.' Rob, parent⁴⁷

47 *The RITE transition: the only way forward*, 2006, Dare Foundation and Ace Centre

? **Who**

Disabled young people, families, Children's Information Service (CIS) workers, Connexions personal advisor/information, advice and guidance (IAG) workers, independent advocates, social workers, education and health staff

? **Where**

Children's and adult services, Children's Information Service (CIS), Connexions partnerships, health services, independent advocacy services, Children and Young People's Strategic Partnership Board (CYPSPB) and Learning Disability Partnership Board (LDPB) transition subgroups

Introduction

Access to high-quality, timely information is one of the issues families say is paramount during the transition process. Some local parent partnership services and children's information services can provide information on the local transition process and some options after school. However, to try and better meet the needs of disabled young people, many local authorities have produced a 'transition pack' for families which gives information on the local transition protocol, potential specialist support services and wider general support services.

Transition pack content

Transition packs should aim to:

- be accessible
- give a clear and easy-to-follow route through the transition process
- provide a glossary of terms and words used
- set out the roles and responsibilities of all agencies involved to ensure that everyone is clear
- provide information about where young people and parents can receive further help and advice.⁴⁸

Generally, local transition packs will cover the following areas as standard:

- what happens during the Year 9 transition review process
- what is available for parents and families
- which local agencies are involved in the formal transition process
- what responsibilities these agencies have, for example; Connexions children's and adult social care services, health agencies and education
- available options after school including Further Education provision, Work Based Learning and day centre options
- what benefits and other financial support is available
- any services and support offered by local voluntary, private and community agencies
- details on local housing options
- leisure and play services.

Information for young people

Having a guide to local support and services available to disabled young

⁴⁸ CDC transition map research, unpublished

people going through the transition process can be extremely useful. It is helpful therefore to have a reference guide to local services which can be accessed and consulted as needed. Some areas accompany this pack with web based information which is kept updated; for example the No Limits website in Suffolk www.nolimits.org.uk.

Effective practice

The most effective transition packs are developed with the participation of disabled young people and families. As well as giving them a sense of ownership, this ensures that information included is relevant and of interest to those intending to use it.

Leicester City spent time working with the local parent carer council and professionals from a range of agencies to produce transition guidance for local disabled young people and their families. The work was led by the Connexions service and involved all agencies offering support at transition. This included local voluntary sector organisations.

The guidance pack includes information on a wide range of local services, details of what local agencies can offer, and a clear 'pathway' chart to outline the transition process. The pack is periodically updated and contains an evaluation form for people to send in comments and ideas for the next edition.

Further examples of transition guides can be found at the following local authority websites:

- Halton www.halton.gov.uk
- London Borough of Waltham Forest www.lbwf.gov.uk
- Worcestershire www.worcestershire.gov.uk
- Surrey www.surreycc.gov.uk

Quality standards checklists

Checklists C2 and C3 in Appendix 6 highlight factors in the process of developing transition guidance packs that have proved useful.

Key legislation, guidance and resources

All recent legislation with regard to the needs of children has included some reference to the importance of choice and having the right information and guidance available. Most recently this includes:

The Children Act 2004

Disability Discrimination Act 2005

Education Act 2002

Education and Inspections Act 2006**NHS Act 2006**

Childcare Act 2006. Enhances role of Children's Information Services. *All Change: Transition into adult life – a resource for young people with learning difficulties, family carers and professionals*, 2003, currently being updated. www.hft.org.uk/writtenmaterials.

Further information on legislation and guidance can be found in the resources pages at the back and in Appendices 1 and 2.

Leisure services

'If you are a disabled person you have to book in a totally different way to everybody else. You often have to phone a different number, you have to speak to different people who are 'special' people.' Alex, aged 17⁴⁹

? Who

Disabled young people, families, statutory and private leisure providers, play providers

? Where

Local play and leisure provision, extended schools

Introduction

Local leisure provision includes sports and leisure centres, cinemas, parks and play spaces. As young people grow up, leisure time is increasingly used to explore their own interests and spend time making new relationships and relying less on their families. Disabled young people may need additional support in order to share this experience.

Current developments

Local authorities may now have Youth Opportunity Funds to be spent on local projects that young people are involved in choosing and developing. For further information see www.everychildmatters.gov.uk

Effective practice

In some areas families and disabled young people have chosen to use Direct Payments to participate in activities with the help of a personal assistant. In other areas, time allocated for short breaks has been used to access a range of formal and informal leisure activities. A number of local authorities now offer leisure passes to disabled young people and carers so that they can claim a range of discounts at local leisure centres.

⁴⁹ *The RITE transition: the only way forward*, 2006, Dare Foundation and Ace Centre

Newcastle: Young Disabled People's Project

The grant-funded Young Disabled People's Project delivers a programme of leisure activities for disabled young people. The programme, which is part of Disability North in Newcastle, includes swimming, trampolining, basketball, five-a-side, bowling skills development and friendship.

Northumberland

Following consultation with young disabled people, Northumberland Children's Fund and Northumberland Sport began work together to lower the barriers that prevent disabled children accessing sports activities. All disabled children and their families in Northumberland are entitled to Max Cards for free or reduced admission to historical and cultural places of interest. Leisure service providers and district councils have agreed Max Card holders will also be entitled to reduced-cost activities in leisure centres.

At **Treloar College**, the occupational therapist works with young people to look at how they can use standard equipment available in all public gyms and leisure centres. So, rather than relying on specialist equipment at the college, the young people can prepare for life after college when they will be living independently in the community with no special equipment at hand.

Further examples of effective practice are available from www.transitioninfonynetwork.org.uk

Quality standards checklists

Involving local play and leisure providers in local authority planning for transition support can help them better understand the needs of disabled young people and plan to meet them effectively. Checklists C6 and C7 in Appendix 6 cover this information.

Key legislation, guidance and resources

The **Disability Discrimination Act 1995**, **Special Educational Needs and Disability Act 2001** and the **Disability Discrimination Act 2005** require leisure services and activities for young people to be accessible.

Education and Inspections Act 2006. Brings in duties on schools to provide a range of flexible activities. This links with the development of extended schools provision.

Youth Matters 2005 and *Youth Matters, the next steps 2006*. Local authorities should use their resources to ensure equal access to leisure facilities for disabled young people.

Planning for Play. Guidance on the development and implementation of a local play strategy, 2006, National Children's Bureau and the Big Lottery Fund. This guidance on the development and implementation of a local play strategy, states that 'An essential feature of the play strategy should be that it promotes inclusion and access for disadvantaged and disabled children and young people.'

Further information on legislation and guidance can be found in the resources pages at the back and in Appendices 1 and 2.

Youth services and activities

*'I love going to club. I have friends there and I like it. But I'm always put in the group making easy crispy cakes.'*⁵⁰

? Who

Disabled young people, families, local authority youth workers, managers of youth services, voluntary and private youth workers, extended services staff, play providers

? Where

Local authority youth centres, voluntary and private youth centres, extended schools, play services

Introduction

Every local authority in England has a duty to commission positive activities for 'vulnerable' groups of young people.⁵¹ A great deal of this activity is provided by the voluntary and community sector and youth services. For disabled young people in transition to adulthood, access to youth clubs and other organised activity are often one of the few opportunities they have to meet up with their peers and make friends. This is particularly the case for disabled young people who attend special schools or out of authority placements away from their local community.

Access to youth services

In many areas, youth services offer a range of activities for all young people. However, access and inclusion for disabled young people to activities is often dependent on a range of factors, which include:

- transport to the service
- accessible building
- skills and knowledge of staff
- letting staff know in advance of particular needs
- an environment in which young people feel safe.

⁵⁰ Research in local youth provision – support for disabled young people, 2005, Council for Disabled Children. Unpublished
⁵¹ Local authorities have a duty to secure for qualifying young people in its area, so far as reasonably practicable, access to sufficient educational and recreational leisure-time activities ('positive activities') and facilities for these. Education and Inspections Act 2006

The focus of much support is centred on individual disabled young people accessing a specific service on a specific night. In an attempt to offer wider, more creative opportunities many areas have developed 'special' nights which are set up to support disabled young people to access the service. While these nights can offer a safe and welcoming environment, it is important that youth services build the skills and confidence of those disabled young people attending and plan for them to access mainstream youth provision when they are ready.

Effective practice

Nottinghamshire have 11 inclusive youth services which are open to all young people. Young people with a range of impairments attend each centre. The services run throughout the year with additional activities in school holidays including residential trips.

Sheffield's Stepping Stone is a central base which co-ordinates youth work activities for disabled young people. They offer advice and will make referrals, if appropriate. They also run youth club sessions, as well as a summer scheme for 14–18 year olds.

Stepping Stone is made up of a joint team of Youth Workers and Connexions workers working with disabled young people. The integration of the two disciplines facilitates a greater degree of joined up services for disabled young people as they make their child to adult transition. The role of the non-formal lifeskills curriculum and vocational support for young people who don't necessarily follow conventional paths into education and employment is often better approached together.

Further examples of effective practice are available from www.transitioninfonynetwork.org.uk.

Quality standards

Youth services can play an important part in disabled young people's social lives. The checklists in Appendix 6 offer a starting point for developing accessible and inclusive activities.

Key legislation, guidance and resources

Section 6 of the **Education and Inspections Act 2006** inserts new sections 507A and 507B into the **Education Act 1996**. Section 507B imposes a new duty on local authorities to secure for young people in their area, so far as reasonably practicable, access to sufficient educational and recreational leisure-time activities which are for the improvement of their well-being, and facilities for such activities. Young people who fall within the scope of this section are all 13–19 year olds, and young people with learning disabilities up to their 25th birthdays. Authorities must consult with young people on existing provision and take their views into account when securing access to these activities. Authorities are also required to publicise information about the positive leisure-time activities and facilities for these activities which are available in its area, and keep this information up to date.

www.teachernet.gov.uk or www.everychildmatters.gov.uk

Aiming High for Young People: a ten year strategy for positive activities, July 2007, DCSF and HM Treasury

Youth Matters green paper 2005 Youth Matters next steps 2006

Russell Commission: A national framework for youth action and engagement (2005). The proposals set out a strategy to attract one million more young people into volunteering within five years, and deliver ‘a step change in the diversity, quality and quantity of young people’s volunteering’.

www.cabinetoffice.gov.uk/russellcommission/report/index.htm

Spotlight, Education and Inspections Act 2006, Youth work and young people, National Youth Agency www.nya.org.uk

Further information on legislation and guidance can be found in the resources pages at the back and in Appendices 1 and 2.

Housing

‘I chose this house. I looked at two other houses and didn’t like them so this was the best one I picked because this house has got a lot to offer.’

Amy, on her experience of shared ownership⁵²



Who

Disabled young people, families, local authority housing officers, housing association officers, directors of adult social care services, adult team social workers, Connexions personal advisors, leaving care social workers, occupational therapists, planners, architects



Where

Adult social care services, residential schools/homes, Connexions, local authority housing departments, local authority planning departments, housing associations, young people’s own homes

52 *After School – What’s Possible? Person-centred transition reviews*, DVD 2007, Valuing People Support Team and Partners. www.valuingpeople.gov.uk

Introduction

Most disabled young people, like their non-disabled peers, will want to explore the possibility of living with a greater degree of independence as they reach adulthood. For some disabled young people, this will lead to them moving away from home and living independently. Others may require support to do this. Some disabled young people with complex needs may remain at home but look at other ways to become more independent. For those planning to leave home, the move can be both exciting and challenging.

Choices in living independently

For many disabled young people moving from their family home will be part of the transition process. Beyond private rental and sale arrangements, there are other options which may be available locally.

Supported living

This usually means support from an organisation to find and live independently – with support – in a home chosen by the disabled person. In most cases people enter into a tenancy agreement with the organisation or are supported to rent somewhere independently. Many schemes are for people with learning disabilities. Much of this support is provided through voluntary sector agencies who operate in local areas. The governments 'supporting people' work underpins this.

Shared housing

Or housing based close together is also available in some areas. This is often based on a small number of disabled people sharing a house or flat and having support staff visit a few times a week, or living in, depending on individual need.

Council housing

Most council housing is allocated using a 'points system'. Young disabled people may want to register with their local authority housing department and look at what the options are likely to be. For many disabled young people, they are likely to access housing provided by local housing associations via the council list as many associations specialise in providing housing for specific groups. For example physically adapted property which is fully accessible to wheelchair users.

Housing associations

As stated above, many associations specialise in supporting particular groups. They all have policies explaining their criteria which are available from the associations directly. They will also explain their eligibility criteria. For example whether disabled young people can apply direct or only via the council waiting list system.

Shared ownership

Shared ownership schemes are an increasingly common way to live. The principle is that a share of the property is bought outright with a further share being owned by the scheme and the owner/tenant paying rent on this.

Care homes

Registered care homes usually provide 24 hour support for people and are regulated by an inspection process.

Current developments

A cross-Government review of policy on Independent Living for disabled people is currently taking place. The review is expected to report in autumn 2007 and make recommendations on a number of areas including housing. Further details on the review from www.dwp.gov.uk.

Effective practice

Supporting People money has led to some effective practice for people with learning disabilities around the country. In **Gateshead**, services are supporting people to improve their quality of life and their life chances. Mr Y is a young man with learning disabilities who lived at home with his father. Unfortunately, his father became ill and had to go into long-term care. Mr Y moved into a flat with two other young people. Housing-related support has helped him develop the life skills and confidence he needs to look after himself and maintain his own home. He is now waiting to move into a flat of his own. He is doing a cookery course at college and has a work placement at a local church serving lunch twice a week.

For further examples and effective practice see www.transitioninforonetwork.org.uk.

Quality standards

Further information on effective practice in planning housing and supporting disabled young people to live independently can be found in the resources below and on www.transitioninforonetwork.org.uk.

Key legislation, guidance and resources

Local Government and Housing Act 1986. Local authority housing departments are legally obliged to work with social services in drawing up community care plans and promoting community care through joint policies. In practice, this should mean they address the needs of young disabled people through special needs housing, mainstream housing and through home adaptations and advice.

Disability Discrimination Act 1995. Requires non-discriminatory practice and to make adjustments so that disabled people can access services.

Disability Discrimination Act 2005. Public authorities must promote equality for disabled people.

Housing Grants, Construction and Regeneration Act 1996.

Housing authorities deal with alterations to homes to help disabled people with daily living, by providing disabled facilities grants.

Chronically Sick and Disabled Persons Act 1970. Local authorities are responsible for assisting disabled people which usually means they will help with equipment that can be installed and removed without structural changes.

Fact sheet on housing options, 2004, Foundation for People with Learning Disabilities www.learningdisabilities.org.uk

Supporting people. An initiative to give support to vulnerable groups, including young people, in accessing independent housing options. www.spkweb.org.uk/

Further information on legislation and guidance can be found in the resources pages at the back and in Appendices 1 and 2.

Transport

'From my point of view transport is a means of getting around, making me independent. It allowed me to go to be educated, it allowed me to go to meet friends throughout the country.' Gary, aged 21⁵³

? Who

Disabled young people, families, directors of children's and adult services, local private transport providers, local public transport providers, council planners, commissioners

? Where

Local council transport departments, children's and adult services, primary care trusts

Introduction

Transport is a key issue for disabled young people in both getting to and from school and in accessing after school and leisure activities. To effectively meet the needs of disabled young people, transition services need to be flexible and able to respond to the changing needs of those using transport services.

Access to transport provision

Transport is important not just in terms of education and training; young people need the confidence to use transport for other activities. Research has shown that 10 per cent of disabled young people say that transport is the main barrier to them participating in sporting events⁵⁴ and that a lack of accessible transport can leave them excluded from leisure interests that their non-disabled peers take for granted.⁵⁵ For these reasons, transport needs to be a key issue addressed at transition.

53 Dare Foundation and Ace Centre (2006) *The RITE transition: the only way forward*, 2006 available from;

www.ace-centre.org.uk

54 *Bridging the divide at transition: what happens for young people with learning difficulties and their families?*, 2002, Pauline Heslop, Robina Mallett, Ken Simons and Linda Ward

55 *Young People with a Disability and Sport*, 2001, Sport England

On leaving formal full-time education, disabled young people's transport provision is withdrawn. Research has found that almost three-quarters of parents whose children were still at school wanted post-school travel arrangements to be covered in the transition plan.⁵⁶

Effective practice

Derby Independent Travel Scheme

This scheme was set up in January 2003 in response to the DfES Pathfinder partnership funding initiative, and provides one-to-one training for students age 16 or over with a range of needs attending schools throughout Derby.

Independent travel training – Plymouth

Plymouth City Council has set up a scheme to provide independent travel training to young people with special educational needs aged 14–19 in full time education. Their travel trainers work on a one-to-one basis with students, helping them develop independent travel skills and problem solving skills, as well as providing general support.

Benefits:

- opens opportunities both for learning and job prospects
- increases independence and use of own initiative
- provides greater freedom – less reliant on friends and family
- raises self confidence
- develops social skills.

There are three stages to the training:

- **Accompanied Travel** Trainer escorts the student to and from the local amenities and on a local bus journey to develop travel skills.
- **Supervised Travel** Trainer and student will use public transport to get to and from the student's home. The trainer will find opportunities to discuss 'What If?' scenarios and problem solving during the journey.
- **Independent Travel** Consists of practising relevant routes leading towards independent travel. The student will gradually travel independently for recognised small journeys, leading to total independent travel on the home to school/college journey.

There is then a final assessment where the student will be assessed while travelling independently on a relevant journey.

Once the student has completed the scheme, the trainer will monitor their progress once a term and be available to offer advice and support.

The training takes place approximately twice a week. The Travel Trainer updates parents and school regularly on the progress of

⁵⁶ *Disabled teenagers' experiences of access to inclusive leisure*, 2002, Joseph Rowntree Foundation

the student. The student receives a certificate at the end of the scheme as well as a free bus pass valid for one year – this can be used for their independent school journey and at weekends.

For more information see
www.plymouth.gov.uk/independenttravel.

Further examples of effective practice are available from
www.transitioninfonynetwork.org.uk.

Quality standards

Transport is integral to independence for all young people. Making sure public transport is accessible and contracted transport is effective are huge challenges for local authorities. Checklists C10 and C11 in Appendix 6 give an overview of how transport needs to be part of planning for disabled young people.

Key legislation, guidance and resources

The **Education Act 1996** makes clear that when deciding what transport support by way of both services and financial support to offer, the local authority must specify what transport arrangements can be made available for disabled young people.

Education and Inspections Act 2006 introduces new duties on local education authorities to provide free transport for eligible children, including those with disabilities. These come into force in 2008.

The **Disability Discrimination Act 1995** now covers certain types of land based transport. The Disability Rights Commission (DRC) has produced a Code of Practice on the provision and use of transport vehicles. It outlines the duties under Part 3 of the Disability Discrimination Act 1995, as amended by the Disability Discrimination Act 2005, and supporting Regulations. These new duties came into force in December 2006.

Learning and Skills Act 2000 states that the LSC may provide financial assistance to help with transport costs (section 5). In exercising its powers to provide financial resources, the LSC must 'have regard to the needs of persons with disabilities and/or learning difficulties' (Section 13).

Transport Support Arrangements for Students aged 16–19, 2006/07. Guidance circular for Local Authority led partnerships including further education and sixth forms when drawing up home to school/college transport policies. This circular provides an update of requirements and clarifies duties under the Education Act 1996 (schedule 19 Education Act 2002).

States that:

'It is not acceptable for partners to deny responsibility for students and to pass the 'problem' between one another.

It also states that local authorities should plan cross boundary travel by ensuring that arrangements are in place for students who live in one local authority area but plan to attend provision in a different area. The guidance states that it is not acceptable to have a blanket ban on assisting students who wish to travel across boundaries without considering individual circumstances first.

Planning and access for disabled people: a good practice guide, 2003, Office of the Deputy Prime Minister (ODPM). Refers to local authority local transport plans. www.communities.gov.uk

London Councils Good Practice Guide on 16–19+ Student Transport Support in London, 2005, London Councils (formerly Association of London Government). www.londoncouncils.gov.uk

Motoring and transport pages [www.direct.gov.uk/en/disabledpeople/motoring and transport](http://www.direct.gov.uk/en/disabledpeople/motoring_and_transport)

Disability Discrimination Act 1995 Code of Practice Post 16 Code of Practice (revised) for providers of post-16 education and related services

Further information on legislation and guidance can be found in the resources pages at the back and in Appendices 1 and 2.

Supplementary resources

This section lists a range of documents, packs and websites which are concerned with the transition process. Legislation and guidance are listed in Appendix 2 on page 89.

Chapter 1 The transition process

Publications

A guide for disabled people, those with health conditions, and carers (2005) Department for Work and Pensions. www.jobcentreplus.gov.uk

All change: Transition into Adult Life (2003) Robina Mallett, Margaret Power, Pauline Heslop, Pavilion Publishing. www.pavpub.com

A Young Person's Guide to Special Educational Needs: Life at school and choices at 16+ (2004) Enquire. www.enquire.org.uk

Career Success of Disabled High-flyers (2005) Sonali Shah, Jessica Kingsley Publishers. www.jkp.com

Enhancing Quality of Life Resource Pack (2002) Facilitating transitions for people with profound and complex learning difficulties. www.skill.org.uk

Your rights at work: A guide for people with a learning disability and their supporters (2006) Disability Rights Commission

Reports

Learning Disability Task Force: Annual Report 2004 – Challenging, Listening, Helping to Improve Lives (2005) Learning Disability Task Force, Department of Health. www.dh.gov.uk

Learning for Living and Work: Improving Education and Training Opportunities for People with Learning Difficulties and/or Disabilities (2006) Learning and Skills Council. www.lsc.gov.uk/Publications/Recommended/Learning-for-Living-and-Work.htm

Moving on up? Negotiating the transition to adulthood for young people with autism (2007) The National Autistic Society. www.nas.org.uk

Seven Principles For Inclusive Transition Planning, The Final Report Of An East Of England Project On Assessment And Transition Planning (2004) East Together – LSC Eastern Region. www.lsc.gov.uk

Through Inclusion to Excellence: The Report of the Steering Group for the Strategic Review of the LSC's Planning and Funding of Provision for Learners with Learning Difficulties and/or Disabilities across the Post-16 Learning and Skills Sector (2005) Learning and Skills Council. www.lsc.gov.uk

Websites

Moving On Up. Website for disabled young people from BME communities. www.movingonup.info

No Limits. Suffolk transition information. www.nolimits.org.uk

Person-centred Planning in Hampshire. A website about person-centred planning working in Hampshire. www.pcp-in-hampshire.net

Skill: National Bureau for Students with Disabilities. www.skill.org.uk

Trans-active. A website for teenagers with learning disabilities by Mencap. www.trans-active.org.uk

DVDs

Proper Hard Work; Training material exploring the learning experiences of disabled young people on vocational course. 2006 Learning and Skills Network. www.lsneducation.org.uk

Chapter 2 Statutory services – an overview

Publications

Acquired Brain Injury exemplar (2004) Department of Health. www.dh.gov.uk

Adolescent Transition Care: Guidance for Nursing Staff (2004) Royal College of Nursing. www.rcn.org.uk

Chronic Fatigue Syndrome (CFS) and Myalgic Encephalopathy (ME) exemplar (2004) Department of Health. www.dh.gov.uk/assetRoot/04/09/81/25/04098125.pdf

Complex disability exemplar: National service framework for children, young people and maternity services (2005) Department of Health www.dh.gov.uk

Deaf Children: Positive Practice Standards in Social Services (2002) Association Of Directors Of Social Services, British Deaf Association, Local Government Association, National Children's Bureau, The National Deaf Children's Society, The Royal National Institute For Deaf People. www.rnid.org.uk

Direct Experience: a guide for councils on the implementation of direct Payments in children's services (2004) Jeanne Carlin and Christine Lenehan, Council for Disabled Children. www.ncb.org.uk/cdc

Future Positive: A Resource Guide for People Working With Disabled Care Leavers (2004) Jill Harris in partnership with the South West working group on disabled care leavers, published by the Department for Education and Skills. www.everychildmatters.gov.uk

Getting a Life: e-news publication produced four times a year with updates on the latest policy and practice developments regarding all aspects of the transition process. www.transitioninfonetwork.org.uk

Hurling into a void: Transition to adulthood for young disabled people with 'complex health and support needs' (1999) Jenny Morris, Pavilion Publishing in association with the Joseph Rowntree Foundation. www.jrf.org.uk

Integrated multi agency transitional care pathway for young people with life threatening and life limiting conditions, 2007, Association for Children's Palliative Care. www.act.org.uk

Improving Transition Planning for Young People with Special Educational Needs (2006) Lesley Dee, Open University Press

Information Pack for Transition Champions (2001) Valuing People Support Team. www.valuingpeople.gov.uk

Information To Support Connexions Partnerships In Their Work With Young People With Learning Difficulties And Disabilities (2002) Connexions Service National Unit. www.connexions.gov.uk

Joint planning and commissioning framework for children, young people and maternity services; processes for joint planning and commissioning (2006) Department for Education and Skills. www.everychildmatters.gov.uk/strategy/planningandcommissioning

Moving on up with diabetes: the transition from paediatric to adult care (2003) Jessica Datta, National Children's Bureau.

My Money, My Way – A Young Person's Guide to Direct Payments (2004) Scope. www.scope.org.uk

Out and about in London: My guide. A guide for people with learning difficulties (2005) Transport for London. www.tfl.gov.uk

Pathways to success – A good practice guide for children's services in the development of services for disabled children: evidence from the pathfinder children's trusts (2006) Council for Disabled Children. www.everychildmatters.gov.uk

Raising Aspirations – Resource Pack (2006) DARE foundation and ACE Centre. www.ace-centre.org.uk

Transition: Getting it right for young people – Improving the transition of young people with long term conditions from children's to adult health services (2006) Department for Education and Skills and the Department of Health. www.dh.gov.uk

You're Welcome quality criteria: Making health services young people friendly (2005) Department of Health. www.dh.gov.uk

Reports

Breaking the Cycle: Taking Stock of Progress and Priorities for the Future (2004) The Social Exclusion Unit, Office of the Deputy Prime Minister. http://archive.cabinetoffice.gov.uk/seu/docs/bc_takingstock.pdf

Bridging the divide at transition: what happens for young people with learning difficulties and their families? (2002) Pauline Heslop, Robina Mallett, Ken Simons Linda Ward. www.bild.org.uk

Bridging the Gaps: Health Care for Adolescents (2003) Royal College of Paediatrics and Child Health, by the Intercollegiate Working Party On Adolescent Health. <http://www.rcpsych.ac.uk/files/pdfversion/cr114.pdf>

Creating Sustainable Communities: Supporting Independence, Consultation on a Strategy for the Supporting People Programme (2005) Office of the Deputy Prime Minister. www.spkweb.org.uk

Disabled children in residential placements, independent researcher (2005) Anne Pinney. www.everychildmatters.gov.uk

Disabled People and Direct Payments: a UK comparative Study Implementing direct payments for disabled people in the UK: initial findings from interviews with purchasing (2005) Mark Priestley. www.leeds.ac.uk/disability-studies/projects/UKdirectpayments/UKDPfinal.pdf

Growing up matters: Better transition planning for young people with complex needs (2007) Commission for Social Care Inspection. www.csci.org.uk/about_csci/publications/growing_up_matters.aspx

Growing Up Ready for Emerging Adulthood: An evidence base for professionals involved in transitional care for young people with chronic illness and/or disabilities (2006) Janet E McDonagh. www.dh.gov.uk

Pathways to work – research on incapacity benefits – evaluation of pilots. www.york.ac.uk/inst/spru/research/summs/incapben.htm

People, not budgets: Valuing disabled children (2004) Florence Heath and Richard Smith, Centre for Policy Studies. www.cps.org.uk

Residential schools and disabled children: decision making and experiences (2001) Joseph Rowntree Foundation. www.jrf.org.uk

The Surest Start – Improving the Life Chances of Young Disabled People (2006) Disability Rights Commission

Transitions: Young Adults with Complex Needs (2005) Social Exclusion Unit, Office of the Deputy Prime Minister. <http://archive.cabinetoffice.gov.uk/seu>

Journal articles

'Barriers and good practice in transition from paediatric to adult care', Russell Viner, *Paediatrics & Child Health*, 28 November 2000

'Lost in transition? Between paediatric and adult services: It's time to improve the transition of adolescents from paediatric to adult services', Janet E McDonagh & Russell M Viner, *British Medical Journal*, Volume 332, 25 February 2006

'On the road to nowhere? Young disabled people and transition', B. Beresford, *Child: Care, Health and Development*, Volume 30, Number 6, November 2004

'Transition from paediatric to adult neurological services', R M Kent and M A Chamberlain, *Journal of Neurology, Neurosurgery and Psychiatry with Practical Neurology*, Volume 75, 2004

Websites

Every Child Matters: Change for Children is a new approach to the well-being of children and young people from birth to age 19.
www.everychildmatters.gov.uk

Every Disabled Child Matters: Getting rights and justice for every disabled child. www.edcm.org.uk

Transition Information Network. www.transitioninforonetwork.org.uk

Valuing People – Valuing People is the government's plan for making the lives of people with learning disabilities and their families better.
www.valuingpeople.gov.uk

DVD

Transition: Getting it Right, a film by Greg, Toyah, Craig, A.J. and Chris.
Email: MB-Childrens-Health@dh.gsi.gov.uk

Chapter 3 Participation and further support

Publications

A lot to say: A guide for social workers, personal advisors and others working with disabled children and young people with communication impairments (2002) Jenny Morris, Scope. www.scope.org.uk

All change: Transition into Adult Life (2003) Robina Mallett, Margaret Power, Pauline Heslop, Pavilion Publishing www.pavpub.com

A Young Person's Guide to Special Educational Needs: Life at school and choices at 16+ (2004) Enquire www.enquire.org.uk

Delivering Housing Adaptations for Disabled People: A Good Practice Guide (2004) Office of the Deputy Prime Minister, Dept of Health and Dept for Education and Skills

Diversity Matters (2006) Council for Disabled Children. www.ncb.org.uk/cdc

Getting there and back again: Guidelines for learning providers on travelling to learning for adults with disabilities or learning disabilities, 2006, Nightingale, C., NIACE

Growing Up Speaking Out: A Guide to Advocacy for Young Learning Disabled People in Transition (2005) The Sounds Good Project and Advocacy Resource Exchange (ARX). www.advocacyresource.net

Linking Up: Emotional Support for Young People with Learning Disabilities (2005) Foundation for People with Learning Disabilities. www.fpld.org.uk

Measuring Up: A toolkit for improving advocacy practice, includes a Disability Discrimination Act audit specifically designed for advocacy projects. www.childrenssociety.org.uk

Tomorrow's big problem: housing options for people with autism: a guide for service commissioners, providers and families (2004) Maurice Harker and Nigel King, The National Autistic Society. www.nas.org.uk

Transition Next Steps: the newsletter for Surrey parents and carers of young disabled people in transition from school to adult life (2006) Partnership with Parents. www.pwpsurrey.org

Travel Training: Good Practice Guidance (2005) Greater Manchester Passenger Transport Executive (GMPTE). www.gmppte.com/upload/library/training_guide.pdf

Transition in England and Wales (2006) Factsheet by Contact a Family www.cafamily.org.uk/transition

Reports

Building a Culture of Participation – Involving children and young people in policy, service planning, delivery and evaluation (2003) A research report on the experiences of 29 organisations in seeking to listen to young people and to act on what they said. The accompanying handbook focuses on how to listen children, illustrating the benefits and how to create the right environment and culture. Available from dfes@prolog.uk.com

Disability and Housing, part of *The Big Picture Series* (2002) The Housing Corporation. www.housingcorp.gov.uk

Disabled teenagers' experiences of access to inclusive leisure (2002) Joseph Rowntree Foundation. www.jrf.org.uk

Disability and transition to adulthood: Achieving independent living (2002) Nicola Hendeby and Gillian Pascall, Pavilion Publishing. www.pavpub.com

Supported Employment for People with Learning Difficulties (1996) Joseph Rowntree Foundation. www.jrf.org.uk

Unaddressed: The housing aspirations of young disabled people in Scotland (2003) Jo Dean, The Joseph Rowntree Foundation. www.jrf.org.uk

Young People with a Disability and Sport (2001) Sport England. www.sportengland.org

Websites

British Association for Supported Employment. www.afse.org.uk

Housing Options: A Housing Advisory Service for People with Learning Disabilities. www.housingoptions.org.uk

Parent Carer Council based in Leicester. www.parentcarercouncil.co.uk

Young Person's Guide to the Residential Special Schools Standards. www.rssinfo.org.uk

Contact a Family – for families with disabled children www.cafamily.org.uk

Further resources

Visit the *Transition Information Network* website for further resources. www.transitioninforonetwork.org.uk

APPENDIX 1

Legislation and guidance tables

The following tables have been included to illustrate the range of legislation and guidance each service must have regard to during the transition process. Table 1 is a strategic overview of the ongoing responsibilities of key services. The subsequent tables illustrate responsibilities for each year, from year nine onwards.

Notes to Table 1

*The NSF, page 38, states:

A multi-agency Transition Group is in place. This could be taken on by an existing group that has developed a multi-agency transition strategy. The group:

- a Includes a Transition Champion from the Learning Disability Partnership Board;
- b Has representatives from Connexions Service, the local authority including social care, education and housing, the Learning and Skills Council, health, user representatives and voluntary organisations, and
- c Assumes responsibility for overseeing transitional arrangements at both strategic and operational level and for agreeing inter-agency protocols;

This strengthens guidance set out in the Valuing People White Paper on the formation of Learning Disability Partnership Boards, Transition Groups and Transition Champions.

Table 1 Strategic – ongoing responsibilities during transition

<i>Agency</i>	<i>Responsibility</i>	<i>Legislation and guidance</i>
<ul style="list-style-type: none"> • Director of children's services 	<p>Has overall responsibility for transition in social care and education</p> <p>Sits on the multi-agency Transition Planning Group.*</p>	<p>Children Act 2004</p> <p>Education Act 1996</p> <p>Valuing People: A New Strategy for Learning Disability for the 21st Century, 2001</p>
<ul style="list-style-type: none"> • Director adult social services 	<p>Has responsibility to work with the Director of children's services to ensure that information about adult services is provided to young people approaching the age where they will make the transition from childhood to adult life.</p>	<p>Our Health, Our Care, Our Say, White Paper, 2006, Department of Health</p> <p>The National Service Framework for Children, Young People and Maternity Services 2004</p> <p>Department of Health</p>
<p>Connexions</p> <ul style="list-style-type: none"> • Manager 	<p>Sits on the multi-agency Transition Planning Group*.</p>	<p>Learning and Skills Act 2000</p> <p>The National Service Framework for Children, Young People and Maternity Services 2004</p> <p>Department of Health</p> <p>Valuing People: A New Strategy for Learning Disability for the 21st Century, 2001</p>
<p>Health</p> <ul style="list-style-type: none"> • Primary Care Trust 	<p>Have place on the multi-agency Transition Planning Group*.</p> <p>Health services develop appropriate adolescent/young persons services with a view to enabling smooth transition to comprehensive adult multi-disciplinary care.</p> <p>Establish dialogue between clinicians, management and commissioners and other agencies.</p>	<p>The National Service Framework for Children, Young People and Maternity Services, 2004</p> <p>Department of Health Standard 8 section 7</p> <p>Valuing People: A New Strategy for Learning Disability for the 21st Century 2001</p> <p>Transition: getting it right for young people, 2006, Department of Health</p>
<p>Local authority, health agencies, partner agencies</p>	<p>Public bodies have a duty to promote equality for disabled people. Many services, including local authorities and individual schools, are required to produce a Disability Equality Scheme to show how they are meeting this duty.</p>	<p>Disability Discrimination Act 1995, SEN and Disability Act 2001</p> <p>Disability Discrimination Act 2005</p>

Table 2 Year 9

Agency	Responsibility	Legislation & guidance
Education (Children's Services) <ul style="list-style-type: none"> • Local Authority Officer with responsibility for education 	The head teacher is responsible for calling Transition Review Meeting to review the young person's Statement of SEN and draw up the Transition Plan.	Education Act 1996 The Education (Special Educational Needs) (England) (Consolidation) Regulations 2001
Education <ul style="list-style-type: none"> • Head teacher • SENCO • Form tutor • Learning and Skills Council representative • Further Education 	<p>The LEA must send to the Connexions Service no later than 2 weeks before the start of the school year, a list of all pupils with a Statement of Special Educational Needs in their area, including those who are not in school, who will need a year 9 review.</p> <p>The head teacher must invite parents, a representative from the local education authority, social services and Connexions to the Year 9 review. They must also ensure that health authorities and trusts are informed and should seek the views of young people who may also be invited to the meeting.</p> <p>The LEA must seek information from Social Services as to whether a young person with SEN is disabled.</p> <p>The head teacher must invite:</p> <ul style="list-style-type: none"> • the young person (should always be invited even if decides not to attend) • the young person's parents or guardian • relevant teacher – class tutor or SENCO • representative from LEA • representative from children and adults social care services. • any person the LEA specifies • any person the head teacher considers appropriate. <p>Depending on pupil's needs and the particular circumstances surrounding the AR the head teacher should also invite:</p> <ul style="list-style-type: none"> • an LEA educational psychologist • health service representatives • other closely involved professionals <p>a further effective practice recommendation would be to invite other people important to the disabled young person.</p>	Education Act 1996 The Education (Special Educational Needs) (England) (Consolidation) Regulations 2001 Disabled Persons (Services, Consultation and Representation) Act 1986 Education Act 1996 The Education (Special Educational Needs) (England) (Consolidation) Regulations 2001
Children's services and adult social services <ul style="list-style-type: none"> • director children's services • director adult services • children with disabilities team manager • team manager, adults learning disabilities 	Social workers should identify and attend the year 9 reviews of young people who are eligible for assessment under the Disabled Persons (Services, Consultation and Representation) Act 1986 LEA must under Section 5 of the Disabled Persons (Services, Consultation and Representation) Act 1986 establish whether a young person with a statement is disabled and may require services from the local authority on leaving school.	Disabled Persons (Services, Consultation and Representation) Act 1986

Table 2 Year 9 *continued*

Agency	Responsibility	Legislation & guidance
<ul style="list-style-type: none"> • team manager adults physical disabilities • transition social worker • transition coordinator • social workers • respite workers 		
Connexions <ul style="list-style-type: none"> • manager • specialist personal advisor • personal advisor 	Connexions Personal Advisor must attend year 9 review, and should invite family/carers and all people involved in supporting the young person.	Education Act 1996 (SEN CoP 2001)
Health <ul style="list-style-type: none"> • Paediatrician • GP • Physiotherapist • Occupational therapist • Speech and language therapist • School nurse • Community nurse • CAMHS • Adult services 	Prepare information to feed into transition review (re-assess if necessary). All young people who have a learning disability should be offered a Health Action Plan. Provide specific health inputs to support young people. It is the responsibility of the Primary Care Trust to identify whether the young person is likely to continue to have health care needs when they leave school and to ensure that arrangements are put in place to enable the young person's health care needs to be met when s/he leaves school. Children's services should alert adult services about projected needs so strategic and clinical planning can start to take place.	Education Act 1996 (SEN CoP 2001) Valuing People: A New Strategy for Learning Disability for the 21st Century March 2001 Education Act 1996 (SEN CoP 2001)
Involvement from other agencies <ul style="list-style-type: none"> • advocacy worker • leaving care team manager • housing • parent partnership officer • PCP coordinator • Parents 	Guidance for social workers dealing with Looked After Children encourages them to consider holding the 14+ Statement Review jointly with a statutory Childcare Review. Parents have the opportunity to feedback on progress in achieving goals established in the Transition Plan and contribute to ongoing planning. Parents and young people may need to engage with the professionals involved in the process before the year 9 review meetings and at other times over the following years.	Children Act 1989 (Looking After the Whole Child handbook Section 4) Education Act 1996 SEN Toolkit – Section 10: Transition Planning (2001) Department for Education and Skills

Table 3 Year 10 and 11

<i>Agency</i>	<i>Responsibility</i>	<i>Legislation & guidance</i>
Education (Children's Services) <ul style="list-style-type: none"> • Local Authority Officer with responsibility for education 	The head teacher has responsibility for organising a review meeting at least annually.	Education Act 1996 (SEN Code of Practice 2001)
Education <ul style="list-style-type: none"> • Head teacher • SENCO • Form tutor • Learning and Skills Council representative • Further Education 	Arrange suitable work placement (year 10).	The Education (Amendment of the Curriculum Requirements for Fourth Key Stage) (England) Order 2003, 2002 Education Act (Section 86)
Children's services and adult social services <ul style="list-style-type: none"> • director children's services • director adults' services • children with disabilities team manager • team manager adults learning disabilities • team manager adults physical disabilities • transition social worker • transition coordinator • social workers • respite workers 	Social services identify which young people with statements likely to leave school at end of Year 11 are disabled. It is good practice to identify young people on SA and SA+ who will need support in adult life. Social Care Services should review the dates when young people will cease to receive fulltime education, either from school or from a further education establishment.	Children Act 1989 NHS and Community Care Act 2000 Disabled Persons (Services, Consultation and Representation) Act 1986
Connexions <ul style="list-style-type: none"> • manager • specialist personal advisor • personal advisor 	PA offers advice and information about post school opportunities, seeks to address barriers to achieving goals, liaising with other agencies as appropriate. PA ensures applications for options post Year 11 are made and timed to meet deadlines. PA works with schools to ensure that, with the young person's permission, full information on progress and support strategies is shared as part of this process. PA liaises with social worker to ensure APIR (assess/plan/implement/review) framework informs ongoing social services assessments and care plans and that Person-centred Planning underpins the process. PA ensures young person knows how to access support in next placement, introducing to new PA where appropriate.	Learning and Skills Act 2000

Table 3 Year 10 and 11 *continued*

Agency	Responsibility	Legislation & guidance
	<p>Arrangements must be made for a Section 140 assessment to be conducted by Connexions during the stated young person's last year of compulsory schooling if they are intending to move on to further education or training. Connexions can carry out Section 140 assessments for non-stated young people as well.</p>	Learning and Skills Act 2000
	<p>When the young person enters their final year in school the PA is required to draw up an action plan with the young person and relevant agencies, including the local Learning and Skills Council and potential providers, that builds on and takes forward the transition plan when the LEA's involvement ceases</p>	Learning and Skills Act 2000
<p>Health</p> <ul style="list-style-type: none"> • Paediatrician • GP • Physiotherapist • Occupational therapist • Speech and language therapist • School nurse • Community nurse • CAMHS • Adult services 	<p>Health professionals including Paediatricians (and their associated teams) should begin to introduce the concept of transition long before it becomes an issue. As part of this programme, the doctor should introduce the concept early so that the young person could be seen by themselves in clinic visits or with someone of their own choice, with parents invited to join the session later.</p> <p>Consider information transfer. Young people with long term conditions often have bulky medical records – it can take several hours to produce a multidisciplinary summary of their history and management in a way that will be useful to someone taking over their care. Paediatric teams should liaise with adult teams to ask what information is most useful. Giving young people copies of key letters and summaries to keep in a Personal Health Record, Health Passports and ensuring that GPs are kept fully informed are helpful strategies.</p>	<p>Department of Health 2006: Transition: getting it right for young people</p> <p>Department of Health 2006: Transition: getting it right for young people</p>

Table 4 Year 12 onwards

Agency	Responsibility	Legislation & guidance
<p>Education (Children's Services)</p> <ul style="list-style-type: none"> • Local Authority Officer with responsibility for education <p>Education</p> <ul style="list-style-type: none"> • Head teacher • SENCO • Form tutor • Learning and Skills Council representative • Further Education 	<p>Curriculum activities including work experience and other activities are provided in accordance with individual needs and goals.</p> <p>LSC and partner agencies include information from S140s in process of identifying gaps in provision.</p> <p>The head teacher together with the Connexions Service should facilitate the transfer of relevant information to ensure that young people receive any necessary specialist help or support during their continuing education and vocational or occupational training after leaving school.</p> <p>Making arrangements for residential college provision where appropriate.</p>	<p>Education Act 1996</p> <p>The Education (Special Educational Needs) (England) (Consolidation) Regulations 2001</p> <p>Learning and Skills Act 2000</p> <p>Education Act 1996 (SEN Code of Practice 2001)</p>
<p>Children's services and adult social services</p> <ul style="list-style-type: none"> • director children's services • director adults' services • children with disabilities team manager • team manager adults learning disabilities • team manager adults physical disabilities • transition social worker • transition coordinator • social workers • respite workers 	<p>Social workers carry out the same procedures that were carried out for Year 11 leavers in the young person's last year at school, including liaison to ensure coherent planning and the identification of disabled young people.</p> <p>Social worker ensures transfer to adult services is affected in accordance with local protocols.</p> <p>Social Care Services should review the dates when young people will cease to receive fulltime education, either from school or from a further education establishment.</p>	<p>Disabled Persons (Services, Consultation and Representation) Act 1986</p>
<p>Connexions</p> <ul style="list-style-type: none"> • manager • specialist personal advisor • personal advisor 	<p>PAs can carry out the same procedures that were carried out for Year 11 leavers in the young person's last year at school, including S140 Assessments, liaison to ensure coherent planning and the identification of disabled young people.</p> <p>PA supports young people applying to HE and liaises with social worker over care needs and direct payments.</p> <p>When the young person enters their final year in school the PA is required to draw up an action plan with the young person and relevant agencies, including the local Learning and Skills Council and potential providers, that builds on and takes forward the transition plan when the LEA's involvement ceases.</p>	<p>Learning and Skills Act 2000</p> <p>Education Act 1996 (SEN Code of Practice 2001)</p>

Table 4 Year 12 onwards *continued*

<i>Agency</i>	<i>Responsibility</i>	<i>Legislation & guidance</i>
Health <ul style="list-style-type: none"> • Paediatrician • GP • Physiotherapist • Occupational therapist • Speech and language therapist • School nurse • Community nurse • CAMHS • Adult services 	Young person should be in process of transferring from paediatric to adult health services, depending on needs and readiness. Set up a preparation period and education programme for the young person and parent: Identification of the necessary skill-set to enable the young person to function in the adult clinic. The young person must acquire the knowledge and skills to function in an adult service, largely independent of parents and staff, before they are transferred.	The National Service Framework for Children, Young People and Maternity Services 2004 Department of Health Transition: getting it right for young people, 2006, Department of Health

APPENDIX 2

Legislation, guidance and government reports

The following listing covers the main legislation, guidance and policy from Government which has an impact on the transition to adulthood for disabled young people. Appendix 3 covers the assessment processes which stem from much of this legislation separately.

At the time of writing, a number of new bills, reviews and consultations were in place which may have a significant impact on the transition process for disabled young people. For up to date information on consultations and proposed legislation see www.dcsf.gov.uk/consultations and www.dwp.gov.uk. The Transition Information Network website also has details. Details on further guidance and effective practice from government is available from www.transitioninforonetwork.org.uk.

International

UN Convention on the Rights of the Child 1989 (UNCRC)

The UNCRC is an international treaty which was ratified in the UK in 1991. Articles 12 and 13 of the Convention enshrine the right of all children to express their views and for these to be taken into account in decisions that affect them. Further to this, Article 23 focuses specifically on disabled children and young people, recognising their right to dignity, independence and participation within their community.

www.unicef.org.uk/youthvoice/pdfs/uncrc.pdf

www.everychildmatters.gov.uk/uncrc

United Nations Convention on the Rights of Persons with Disabilities, 2006

Adopted by the UN General Assembly, December 2006, UN signature ceremony 30 March 2007. Then individual countries will ratify.

Embodies the rights of disabled people to equal participation in public, political (Article 29), cultural life (Article 30) and within their community (Article 19). The convention also states that disabled children and young people should have access to the same rights and freedoms as all children, with particular reference to ensuring they have the right to express their views on all issues which affect them and to be provided with the appropriate support to enable them to do so (Article 7). This is supported by Article 21 which states that to enable disabled people to exercise their right to freedom of expression, states parties should take steps to ensure that they are able to receive and impart information using a range of formats,

including assistive and augmentative communication, and that information provided to the general public should be made available to disabled people in a range of accessible formats.

www.un.org/esa/socdev/enable/index.html

England

At the time of writing, HM Treasury are in the process of reporting on a review of children's services. One aspect of this review focused specifically on services for disabled children, young people and their families. In May an announcement was made on the disabled children's aspect of the review. Details of this are in the report *Aiming High for Disabled Children, better support for families*, www.hm-treasury.gov.uk. The transition to adulthood features in the review and the report contains a series of proposed areas for government and local authorities to look at in improving support to disabled young people. This includes:

- provision of information for young people and families
- reviewing person-centred approaches
- using advocacy or key workers for support
- promoting multi agency working.

The review attaches £19 million to support this work. The Department for Children, Schools and Families (DCSF) will release further detail on how this will be taken forward in the coming months.

Key legislation

The Children Act 2004

Makes various amendments to existing legislation including the **Children Act 1989**. Sets the legislative foundation for the actions agreed as a result of Every Child Matters. Includes provision for the establishment of a Children's Commissioner and for each children's service authority in England to make arrangements to promote co-operation between the authority, its partners and other appropriate bodies to improve the well-being of children in the authority's area relating to areas which include physical health, emotional well being and education and training.

States that arrangements made may apply to the 19–25 age group who have a learning difficulty and are receiving services under the Learning and Skills Act.

Sets out a mechanism for establishing a database and sharing information, (Integrated Children's System).

Brings in roles of Key worker and lead professional.

States that the views and wishes of children and young people should be ascertained and given due regard in determining the provision of services to them.

www.everychildmatters.gov.uk

The Children Act 1989

Provides the framework for social care services for children and young people. Includes the need for the views and interests of children to be taken into account. The Act has been amended by numerous statutes.

www.dfes.gov.uk/publications/childrenactreport

The Education Act 1996

The transition review process which forms the main monitoring and planning tool for most disabled young people, is built on this Act and the code of practice issued under it, the **SEN Code of Practice 2001**.

The SEN Code of Practice outlines the statutory assessment process to identify special educational needs for young people who will probably require more support than is given at School Action and School Action Plus.

School Action aims to help young people get additional learning support from their teacher. If the young person does not make adequate progress, the school will offer further support at **School Action Plus** which means involving specialist help from outside. If the young person still does not progress, the school or parent may ask the local education authority to make a Statutory Assessment under sections 329A or 329 of the Education Act 1996. If the authority agrees to carry out a **Statutory Assessment**, the young person will be seen by an Educational Psychologist and a doctor or medical officer, who will advise the local authority on the type of learning support they require. The child's school, any other professional such as a speech and language therapist, and the parents will be asked for advice on the young person's learning difficulties and the provision they need. If the local education authority believes the support needed is greater than generally provided by mainstream schools at School Action Plus they will draw up a **Statement of Special Educational Needs**. This is a document that sets out that young person's needs and states the special educational provision they require. Appeals against the local education authority's decisions on whether to assess and whether to draw up a statement may be made to the Special Educational Needs and Disability Tribunal.

Subsequent legislation relating to pupils with SEN builds on this legislation.

www.opsi.gov.uk/acts/acts1996/1996056.htm.

The Learning and Skills Act 2000

Places a duty on the Secretary of State, through Section 140 of the Act, to make arrangements for the assessment of disabled young people when they are undertaking or likely to undertake post-16 education or training or higher education.

Requires the LSC to have regard to the needs of persons with LDD and to any report of an assessment carried out under Section 140.

Sets out the reasons for seeking a specialist residential placement.

www.opsi.gov.uk/acts/acts2000/20000021.htm

Health and Social Care Act 2001

S57 covers direct payments and extended their use to disabled young people aged 16 and 17. S58 added S17A to the Children Act 1989 which made provision about direct payments in respect of children.

www.opsi.gov.uk/acts/acts2001/20010015.htm

NHS Act 2006

Section 242 of this Act places a duty on Strategic Health Authorities, Primary Care Trusts, NHS trusts and NHS Foundation trusts to make arrangements to involve and consult with persons receiving health services for which these bodies are responsible, or their representatives, in relation to the planning and provision of such services, developments and changes in such services and decisions affecting the operation of those services.

www.opsi.gov.uk/acts/acts2006/20060041.htm

Disabled Persons (Services, Consultation and Representation) Act 1986

The Act was designed to improve the coordination and effectiveness of resources and services for disabled people and those with mental illness. *Its use is now limited as it has been superseded by other legislation and guidance.*

Note that the duty on local authorities under section 8 of this Act to take into account the abilities of the carer is overridden where the Carers (Recognition and Services) Act 1995 applies. The 1995 Act has been amended several times (by the Carers and Disabled Children Act 2000 and the Carers (Equal Opportunities) Act 2004) but is still an important part of the picture.

www.opsi.gov.uk/si/si1987/uksi_19870564_en_1.htm

NHS and Community Care Act 1990

Incorporating the **Chronically Sick and Disabled Persons Act 1970**

Local authorities are required to publish and keep under review a plan for the provision of Community Care services in their area. The Act also places a duty on local authorities to assess individuals' need for services, where they appear to be needed.

www.dh.gov.uk

The Community Care (Direct Payments) Act 1996

The relevant provisions from this Act were repealed by S67 of the Health and Social Care Act 2001.

www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance

Carers and Disabled Children Act 2000

The Act requires local authorities who receive a request for a carer's assessment to assess the carer's needs and provide services which they think are appropriate and will support the carer to continue in their caring role. The services provided may be physical help or other forms of support. No such provision was made in relation to children's services because local authorities can provide services to the family under section 17A of the Children Act 1989. There is some overlap between the Carers (Recognition and Services) Act 1995 and the 2000 Act.

www.everychildmatters.gov.uk

The Carers (Equal Opportunities) Act 2004

This introduced a legal obligation on social services to inform carers of their rights. It ensures that work, lifelong learning and leisure are considered when a carer is assessed. It also allows social services to ask housing, health, and education authorities as well as other local authorities for help to support carers.

www.opsi.gov.uk/acts/acts2004/2004015.htm

The Children (Leaving Care) Act 2000

The Act amends the previous provision for care leavers set out in the Children Act 1989 and is designed to improve the life chances of young people living in and leaving local authority care.

Provides an entitlement to an assessment and a Pathway Plan and a personal adviser for each looked after and former looked after young person to improve the:

- preparation and planning for leaving care
- financial arrangements for care leavers

and to:

- ensure that young people continue to receive the support they need to make an effective transition to adult life.

www.everychildmatters.gov.uk/socialcare/lookedafterchildren/leavingcare/

Disability Discrimination Act 1995

Legislation which set a new definition of disability, places duties on all providers of services to the public, including education, to make services accessible, making reasonable adjustments to do so. Associated codes of practice also available.

www.opsi.gov.uk/acts/acts1995/1995050.htm

www.tso.co.uk

Disability Discrimination Act 2005

Widens the definition of disability, places a new duty on public bodies, including maintained schools, to positively promote disability equality and

not discriminate in carrying out their functions. Local authorities and others are required to draw up a Disability Equality Scheme to illustrate how they are meeting the duty locally. Associated codes of practice also available.

www.opsi.gov.uk/acts/acts2005/2005013.htm

www.tso.co.uk

The Special Educational Needs and Disability Act 2001 (SENDA)

- amends both the **Education Act 1996** and the **Disability Discrimination Act 1995**
- applies to pre- and post-16 education
- makes it illegal to treat a disabled person less favourably than a non-disabled person for reasons related to his/her disability, without justification
- requires institutions to make reasonable adjustments to ensure that a disabled student is not placed at a substantial disadvantage.

Associated codes of practice also available.

www.opsi.gov.uk/acts/acts2001

www.tso.co.uk

Education and Inspection Act 2006

Contains tools to implement Youth Matters, as well as the White Paper, *Higher Standards, better Schools For All*, and the 14–19 Education and Skills White Paper.

Section 6 amends the Education Act 1996 and places a duty on local authorities to improve the well-being of young people aged 13–19 (and up to 25 for those with learning difficulties) by providing access to sufficient educational and recreational leisure-time activities and facilities.

Authorities will be expected to meet these requirements by:

- providing activities and facilities;
- commissioning others to provide activities and facilities; or,
- making other arrangements to facilitate access, including providing information, financial assistance and transportation.

Authorities must consult with young people on existing provision and take their views into account when providing local information on these activities.

www.dfes.gov.uk/publications/educationandinspectionact/

Childcare Act 2006

Measures in the act formalise the important strategic role local authorities play through a set of new duties. These duties will require authorities to:

- Improve the five Every Child Matters outcomes for all pre-school children and reduce inequalities in these outcomes
- Secure sufficient childcare for working parents
- Provide a better parental information service

www.everychildmatters.gov.uk/earlyyears

Guidance and government reports

Every Child Matters 2003

- sets out to ensure that children at risk are properly protected within a framework of universal services, which support every child to develop their full potential.
- sets out a vision for early intervention and effective protection which includes improving information sharing, establishing a common assessment framework, identifying lead professionals
- anticipates the SEN Action Programme – Removing Barriers to Achievement
- says that it will improve the transition to adulthood through the National Service Framework for Children, the SEN Action
- programme and the work of Connexions
- was followed with a consultation and a 'Next Steps' paper.

www.everychildmatters.gov.uk

Every Child Matters: Change for Children 2004

Sets out the action that needs to be taken locally to implement the Children Act, and describes the support that will be provided

www.everychildmatters.gov.uk

The SEN Code of Practice 2001

Code of Practice under the **Education Act 1996**. Describes the annual review process from Year 9 and the place of the transition plan within that process

- describes the responsibilities of Connexions who:
 - must attend the Y9 review and should attend the Y11 review
 - are responsible for overseeing the delivery of the Transition Plan; the PA should co-ordinate its delivery
 - should be involved in the transfer of information
 - must ensure a section 140 assessment is carried out under LSA 2000
- describes the role of Social Services and Health
- acknowledges that young people with SEN who have not required a Statement may require support in transition
- recommends that the Pathway Plan, Transition Plan and Connexions Personal Action Plan should be the same document.

The **SEN Toolkit 2001** adds further detail to this guidance.

www.teachernet.gov.uk/wholeschool/sen/teacherlearningassistant/toolkit

Removing Barriers to Achievement – The Government's Strategy for SEN 2004

- revolves around the key areas of early intervention, removing barriers to learning, raising expectations and achievement and delivering improvements in partnership
- anticipates that most children with SEN will be educated in mainstream schools

- makes a commitment to work across Government to improve the quality of transition planning, setting national standards for health and social care through the children's NSF and to work with the Connexions Service and the LSC to expand educational and training opportunities and develop new opportunities for transition to work.

www.teachernet.gov.uk/wholeschool/sen/senstrategy

National Service Framework for Children, Young People and Maternity Services, September 2004, DH and DfES

Is a ten-year programme intended to stimulate long-term and sustained improvement across all services in children's health.

Section 7 of Standard 8 is on Transition to Adulthood. This sets out:

- a person-centred approach to transition planning, focusing on the fulfilment of the hopes, dreams and potential of the young disabled person.
- the establishment of multi agency transition groups.
- support for young disabled people to use direct payments.
- support to manage the transition for those with high levels of need, those in residential schools, looked after children and those with rare conditions.
- that agencies develop local strategies to widen education, training and employment opportunities for disabled young people.
- the development by Health Services of appropriate adolescent/young persons' services with a view to enabling smooth transition to comprehensive multi-disciplinary care.

www.everychildmatters.gov.uk

Improving the Life Chances of Disabled People, 2005, Prime Minister's Strategy Unit, Cabinet Office

The report considers what could be done to improve opportunities for Britain's 10 million plus disabled people of all ages. It sets out a 20-year vision: 'By 2025, disabled people in Britain should have full opportunities and choices to improve their quality of life, and will be respected and included as equal members of society'.

The report covers four key areas of disabled people's lives:

- independent living
- early years and family support
- transition to adulthood
- employment.

The section on transition highlights three key ingredients needed for effective support for disabled young people, to ensure that they enter adulthood able to participate and be included:

- planning for transition focused on individual needs
- continuous service provision
- access to a more transparent and appropriate menu of opportunities and choices.

www.officefordisability.gov.uk

Valuing People: A New Strategy for Learning Disability for the 21st Century, March 2001

- sets out the new vision for services under the four key principles of Rights, Independence, Choice and Inclusion
- highlights the issues young people face in transition and sets an objective 'As young people with learning disabilities move into adulthood, to ensure continuity of care and support for the young person and their family; and to provide equality of opportunity in order to enable as many disabled young people as possible to participate in education, training or employment.'
- highlights the role of Connexions, including their responsibilities to young people up to the age of 25
- describes the responsibilities of Learning Disability Partnership Boards for
 - establishing frameworks for Person-centred Planning which will build on the assessment and planning work undertaken by Connexions
 - identifying a person with lead responsibility for transition
- notes the importance of continuity in health care
- sets an objective 'To enable more people with learning disabilities to participate in all forms of employment, wherever possible in paid work, and to make a valued contribution to the world of work'.

www.valuingpeople.gov.uk

Our health, our care, our say: a new direction for community services, Health White Paper, 2006, Department of Health (DH)

Directors of Adult Care Services (DASS) to play a central role in ensuring that arrangements are in place to support disabled young people during the transition to adult services, working with directors of children's services.

Department for Education and Skills and other stakeholders to implement the standard on disabled children in the National Service Framework for children, young people and maternity services and the recommendations in the Prime Minister's Strategy Unit report, *Improving the Life Chances of Disabled People*, to improve the support for disabled children and their families and to provide advice and support for disabled young people making the transition to adult services.

Our health, our care, our say: Making it happen, 2006, DH

Implementation details for the White Paper

www.dh.gov.uk/publicationsandstatistics/publications/publicationsstatistics/index.htm

Working Together: Giving Children and Young People a Say, 2004, DfES

Working Together is statutory guidance for Local Education Authorities, governing bodies and schools, to promote and encourage the participation of pupils in decisions which affect them, as required under the Education Act 2002.

www.teachernet.gov.uk

Learning to Listen – Core Principles, 2001, [Children and Young People's Unit]

Sets out core principles for participation and a common framework to increase the involvement and participation of children and young people in the design and delivery of policy and services which affect them.

www.dfes.gov.uk/listeningtolearn/downloads/LearningtoListen-CorePrinciples.pdf

Youth Matters, Youth Green Paper, 2005, DfES

Youth Matters, Next steps, 2006, DfES

Youth Matters, sets out plans for 'Youth Opportunity Funds' in each local area. Also, sets out the government's plans for the future of IAG. *Youth Matters, Next Steps*, 2006, and the Quality Standards for Young People's Information, Advice and Guidance consultation document (2006, DfES) confirms how it proposes to take these plans forward. This includes:

- responsibility for IAG and the funding that goes with it will be devolved from Connexions to local authorities through children's trusts, schools and colleges
- schools and colleges will have the right to commission IAG directly from local providers, including existing Connexions services
- it is proposed agencies will have an option on whether to provide only basic information to young people or, a higher, more comprehensive level of IAG service.

For further information on the outcome of this consultation and updates on the changes to the Connexions service see www.dcsf.gov.uk.

Assessment of Young People with LDD (Connexions) February 2004

- revised guidance including carrying out Section 140 [Learning and Skills Act 2000] assessments which sets them in the context of wider transition planning
- highlights that assessments must be carried out for young people with Statements in their last year of compulsory schooling and for those with SEN but without Statements
- sets out the need for Connexions and the local Learning and Skills Council, (LSC), to agree a format for S140 Assessments and to have a mechanism in place for influencing future service provision.

Information to Support Connexions Partnerships in their Work with Young People with LDD September 2002

- sets out the legal framework and the requirements of Connexions in their work with young people with LDD
- Sets out a framework for supporting young people placed out of area in transition and the responsibilities of home and host PAs. The arrangements are flexible but put most responsibility with the 'host' PA to carry out assessments and attend reviews. However, the 'home' PA is expected to attend the final review if the young person is expected to return to their home area.

<http://www.connexions.gov.uk/partnerships/publications/connexpubs/>

Promoting Disability Equality in Schools and Early Years Settings 2006, Department for Education and Skills

These guidance materials explain how the Disability Equality Duty (DED) can be implemented by schools and early years settings. The Disability Equality Duty does not bring in new rights for disabled people, but it does require schools to take a more proactive approach to promoting disability equality and eliminating discrimination. This guidance looks at pre-existing duties to bring greater benefits to disabled children and young people, staff, parents and others by considering disability equality from the start and at every level of the school. This resource will be added to periodically.

For more information go to www.teachernet.gov.uk/wholeschool/sen/disabilityandthedda/guidancedisabilityequalityinschools

Best practice guidance on the role of Director of Adult Social Services

Every local authority has a Director of Adult Social Services post. Responsibilities include:

- adult social services, with specific role in developing support and working with partner agencies to make transition to adult services successful.

www.dh.gov.uk/en/publicationsandstatistics/index.htm

For further information on up and coming new legislation and guidance see www.commonleader.gov.uk and www.everychildmatters.gov.uk

Assessments at transition

Assessment processes and Information sharing

Two relatively new developments in gathering, storing and sharing information are being implemented in local authorities. The Common Assessment Framework and the Integrated Children's System. They are described below.

Common Assessment Framework (CAF) for Children and Young People

The implementation of the CAF is underway with local areas finding ways to establish this standardised tool most effectively to meet local need and as part of introducing children's trust arrangements by 2008. The process is designed to gather information from families, to more quickly identify children with additional needs. For most disabled children, the CAF works as an initial process, leading to more specialist assessments as needed. For example; access to speech and language therapy services.

For more information: www.everychildmatters.gov.uk/delivering-services/caf/

Integrated Children's System (ICS)

The ICS aims to promote better outcomes for children in need. Local authorities are expected to have the computer software in place to support the ICS for all new referrals. Children's social care services are at the hub of implementing the system and working with it. A number of authorities acted as pilots for the ICS and identified a range of strategies which they found are needed to involve all agencies effectively and make the system work. These strategies included:

- establishing interagency steering groups
- developing interagency briefing and training sessions
- using specialist staff to act as champions for each agency
- focusing on opportunities to share information electronically.

Developing a systematic approach to gathering and keeping information across key agencies should lead to a better, more coordinated response when families request support. The new systems will also hopefully improve things like: clashing hospital appointments, reasonable notice of SEN Reviews and planning meetings, and more transparency in how services are allocated. For more information: www.everychildmatters.gov.uk/socialcare/ics

Core Assessments at Transition

Parents consistently say that a simpler, combined assessment process would improve the quality of their families' life more than almost anything else.¹

¹ Research with local parents groups, 2005, Council for Disabled Children, Unpublished.

The key agencies involved in supporting disabled young people in transition and their families need to use the Common Assessment Framework to avoid young people and parents having to give basic details and tell their stories repeatedly. Where transition teams have been set up, such as in Suffolk and Sandwell, the amount of assessments families and disabled young people have has been reduced substantially. This is due in part to the improved access professionals have to each other as some now share offices. This allows time to work out where their respective assessments can be joined, and how much information can be gathered using joint assessments rather than single appointments with families.

Table of assessments

<i>Assessment</i>		<i>Age of young person</i>
Common Assessment Framework	Initial, basic assessment tool for use by all services. Social care use as first point of contact. 'Gateway' to other more specialist assessments.	Any age – should be used for initial contacts.
Framework for the Assessment of Children in Need and their Families (The Assessment Framework)	Assess and plan support from social services including: <ul style="list-style-type: none"> • Short breaks • Equipment • Direct payments (at 16) 	Until transferred to adult services at 18 or 19.
The Children (Leaving Care) Act 2000	Multi agency assessment and development of a Pathway Plan	15/16
Disabled Persons (services, consultation and representation) Act 1986	Assessment from social care for possible support needed on leaving school or college. Generally, this is not used as has been superseded by other practice.	14 (Year 9)
Education Act 1996 SEN Annual Review/Transition Review	Prepare Transition Plan – Review meeting every year	13/14 (Year 9) up to leaving school or college where kept up.
Learning and Skills Act 2000 – Section 140 Assessment	Assess and plan support for post-school.	16 – or until the young person leaves school.
NHS and Community Care Act 1990 (incorporating the Chronically sick and disabled persons Act 1970)	Formal assessment of need leading to a Care plan Assessment for support from the Independent Living Fund	18 onwards

Current core assessments at transition

This section lists the minimum standard assessments that a disabled young person is likely to have as they move through the transition to adulthood.

Children's Services

Social Care

Framework for the Assessment of Children in Need and their Families (The Assessment Framework)

The guidance documents for the assessment framework are issued under Section 7 of the Local Authority Social Services Act 1970. The guidance is not a statutory requirement but should be complied with unless exceptional local circumstances are in place.

Outline

Produced for use by professionals involved in undertaking assessments of children in need and their families under the Children Act 1989. To provide a framework which could be used across services to establish agreement on the best way to meet individual children's needs. The Common Assessment Framework (CAF) is becoming the initial assessment tool used with families by social care teams. Where there is need for further work to assess and identify need, the Assessment Framework is used. This assessment process, as described below, can be used to cover a number of areas.

'where it appears to a local authority that a child within their area is in need, the authority may assess his needs for the purposes of this Act at the same time as any assessment of his needs is made under:

- *the Chronically Sick and Disabled Persons Act 1970*
- *the Education Act 1996*
- *the Disabled Persons (Services, Consultation and Representation) Act 1986 or*
- *any other enactment'.*

Children Act 1989 (schedule 2 paragraph 3)

Information used for

The Assessment Framework is used in a variety of ways to carry out assessments on a range of areas. This includes assessments for access to:

- direct payments – under the Carers and Disabled Children Act 2000
- short breaks
- safeguarding children
- family support services
- aids and adaptations
- any service provided by children's social services.

If a disabled young person is 'looked after' by the local authority they may also have a range of other assessments which should join with this process.

Children's services

Education

The transition review process which forms the main monitoring and planning tool for most disabled young people, is built on the following legislation and guidance:

- **Education Act 1996**
- **SEN Code of Practice 2001**
- **SEN Toolkit 2001**

The SEN Code of Practice outlines the statutory assessment process to identify special educational needs. The process is set out below, although many disabled young people will be offered an assessment for a statement as a starting point, depending on their levels of need.

School Action aims to help young people get additional learning support from their teacher. If the young person does not make adequate progress, the school will offer further support.

School Action Plus is the next stage which means involving specialist help from outside. If the young person still does not progress, the school or parent may ask the local education authority to make a Statutory Assessment under sections 329A or 329 of the Education Act 1996.

Statutory Assessment As part of this process, the young person will be seen by an Educational Psychologist and a doctor or medical officer, who will advise the local authority on the type of learning support they require. The child's school, any other professional such as a speech and language therapist, and parents will be asked for advice on the young person's impairment and the provision they need. If the local education authority believes the support needed is greater than generally provided by mainstream schools at School Action Plus they will draw up a **Statement of Special Educational Needs**. This is a document that sets out that young person's needs and states the special educational provision they will require. Appeals against the local education authority's decisions on whether to assess and whether to draw up a statement may be made to the Special Educational Needs and Disability Tribunal.

Education Act 1996

Annual Review/Transition Review

The annual review in year 9 and any subsequent annual reviews until the young person leaves school must include the drawing up and subsequent review of a Transition Plan.

SEN Code of Practice Page 130 Paragraph 9.51

Regulations 18 to 21 Education (Special Educational Needs) (England) (Consolidation) Regulations 2001 SI 2001/3455

Outline

Regulations require that a Transition Plan must be prepared for all young people with a statement of special educational needs following the year 9 annual review.² It should build on the plans and targets set in past annual

2 Regs 18 and 21
Education (Special
Educational Needs)
(England)
(Consolidation)
Regulations 2001 SI
2001/3455)

reviews. The head teacher has responsibility for calling the transition review and drawing up the subsequent transition plan. The Connexions service must attend the year 9 review as a condition of their grant, and may oversee the drawing up of the transition plan. A Transition Plan will be drawn up following the meeting and will be circulated to the family and all relevant professionals.

There is no formal assessment linked with transition planning but the SEN Toolkit makes it clear that transition planning must cover:

- what are the young person's hopes and aspirations for the future, and how can these be met?
- what do parents expect of their son's or daughter's adult life?
- what are the young person's curriculum needs during transition?

SEN Toolkit, Page 13.

Potentially, the transition review can cover all aspects of the young persons life and plan for each. Using person-centred approaches in this planning and skills of those attending and the services they represent makes for a highly effective process and support structure for the young person to achieve their goals.

Learning and Skills Act 2000

This act established:

- the Learning and Skills Council with a statutory duty to promote participation in learning after the age of 16
- the Connexions Service to provide integrated support services for all 13 to 19 year olds (up to the 25th birthday for disabled young people where needed), including information, advice and guidance services.

The Connexions service

The Connexions Service provides all 13–19 year olds with access to advice, guidance and support through access to a Personal Advisor.

The Personal Advisers:

- attend annual reviews of all year 9 pupils with statements of SEN
- work with the school and other agencies to 'oversee' transition plans
- can work with all young people and continue to support disabled young people until their 25th birthday where needed.

The role of this service will change from 2008. For more information: www.everychildmatters.gov.uk.

Section 140 Assessment

Section 140 of the Learning and Skills Act requires an assessment of young people with statements of SEN going from school into post 16 education or training or higher education during their last year of schooling. A Section 140 Assessment can also be arranged at any time for a disabled young person without a statement of SEN who is in the last year of compulsory schooling or below the age of 24 if they are in or likely to enter education or training.

Aim

Section 140 Assessments provide information to Local Learning and Skills Councils (LSC) and colleges to help them plan to meet the needs of future students. These assessments are completed in the autumn term if possible so the report can support the application process to college or training. The assessment should build on the information from the last annual review (for young people with Statements) and take into account any Transition Planning, Personal Action Plan or Pathway Plan which is in place.

With permission from the young person the information can be used in a wider context to support them in accessing other services.

The Section 140 assessments can provide a valuable formal mechanism of support for those young people who are likely to move onto college or work-based learning who do not have a statement of SEN, particularly those who are on School Action Plus.

Health services

Health services have an essential role to play in disabled young peoples transition to adulthood, both across health services and in the wider transition process. Whilst there is no statutory 'health transition' requirement, the following legislation and guidance requires health services involvement in the transition process.

Health and Social Care Act 2001

Education Act 1996

Special Educational Needs Code of Practice and SEN Toolkit,
(S12) 2001, DfES

Valuing People: A new strategy for learning disability for the 21st century, 2001, DH

National Service Framework for Children, Young People and Maternity Services, 2004, DH and DfES

Transition: getting it right for young people. Improving the transition of young people with long term conditions from children's to adult health services, 2006, DH

Our health, our care, our say: a new direction for community services, Health White Paper, 2006, DH

Health Action Plans and Health Facilitation: Good Practice Guidance for Learning Disability Partnership Boards, 2002, DH

Action for health, health action plans and health facilitation detailed good practice guidance on implementation for learning disability partnership boards, 2002, DH

Health professionals can make invaluable contributions to the wider transition planning process which is led by other agencies. Although attending each formal review may be difficult, contributing information from contact with individual disabled young people is essential to the process. Each health service has a series of assessments which are carried out during appointments with disabled young people. As well as medical

needs, questions about communication, access to learning, mobility, self-care, independent living, and special equipment may be discussed. This information can be contributed (with permission) to the main transition planning process to help ensure effective support is planned for. Where a young person has a specific medical condition (and other agencies have so far had limited input), a health professional may take a lead in initiating transition planning, alerting other agencies as appropriate.

The transition from paediatric to adult health services is covered in a range of guidance and, in response to the NSF, the Department of Health have produced guidance for implementing a process to make the transition from paediatric to adult health services a positive experience for those with complex health needs (see legislation box above). This work translates well to include all disabled young people. Many areas and specialist teams are developing adolescent teams to bridge this time and are reporting some success.

For more information on this emerging area of practice

The Care Services Improvement Partnership supports positive changes in services and in the wellbeing of vulnerable people with health and social care needs. www.csip.org.uk

The Department of Health provides health and social care policy, guidance and publications. www.dh.gov.uk

The National Service Framework for children, young people and maternity services, published on 15 September 2004, sets standards for children's health and social services, and the interface of those services with education. www.dh.gov.uk/en/Policyandguidance/Healthandsocialcare/topics/Childrensservices/Childrenservicesinformation/index.htm

Practice examples

1 Health Action Plans

Valuing People¹ stresses the need for all disabled young people approaching the end of their secondary schooling to have a Health Action Plan (or Health Plan). The drawing up of a Health Action Plan can make sure disabled young people continue to have access to services they need to stay healthy and not fall between services as they move between paediatric and adult health services and move from school arranged health support. For disabled young people who do not have a statement of special educational need, having a HAP can be particularly useful as they are unlikely to have health concerns and issues addressed in other forums as they may not have a standard annual review.

In some areas, health action plans are developed from the Year 9 transition review. Like the wider transition review, the compilation of a health action plan, (HAP) is a process rather than a one off event. It can take some months to bring together all the necessary information from a range of health professionals to ensure all aspects of a young person's particular health support needs are covered. Working with other agencies in the lead up to a review and using existing appointments with the young person and their families to discuss what the plan should contain can help speed up this process.

A transition health action plan might contain the following:

- Medical management of a long-term condition and how a young person might develop skills in monitoring and self-management
- Access to generic health advice
- Strategies for maintaining psychological well-being, social skills and self-esteem
- Support access to the educational curriculum, work experience or employment (vocational opportunities)
- Developing abilities and strategies for improving/maintaining physical skills and mobility, self-care (dressing etc.) and independence (including use of community facilities)
- Identification of specialist equipment and environmental adaptations (including housing)

HAPs need to be updated regularly for them to be useful and this can be a problem if the young person is discharged. Once again mechanisms need to be in place to make sure that a lead person is identified to keep these plans live. Drawing up a health action plan can help focus all agencies on issues of importance to the young person, concerns they may have and what can be put in place to support them. This extends beyond issues relating to their impairment and could include access to personal, social and health education, (PSHE) including sex and relationships, and healthy eating. It is therefore essential that this is part of the wider transition planning process.

- 1 Health Action Plans
- 2 RCN Clinical Pathway for adolescent transition
- 3 Yorkshire and Humberside Partnership Priority Group on Transition
- 4 Multi Agency Pathway – Leicester City
- 5 Strategic and Operational Planning at Transition – the quest

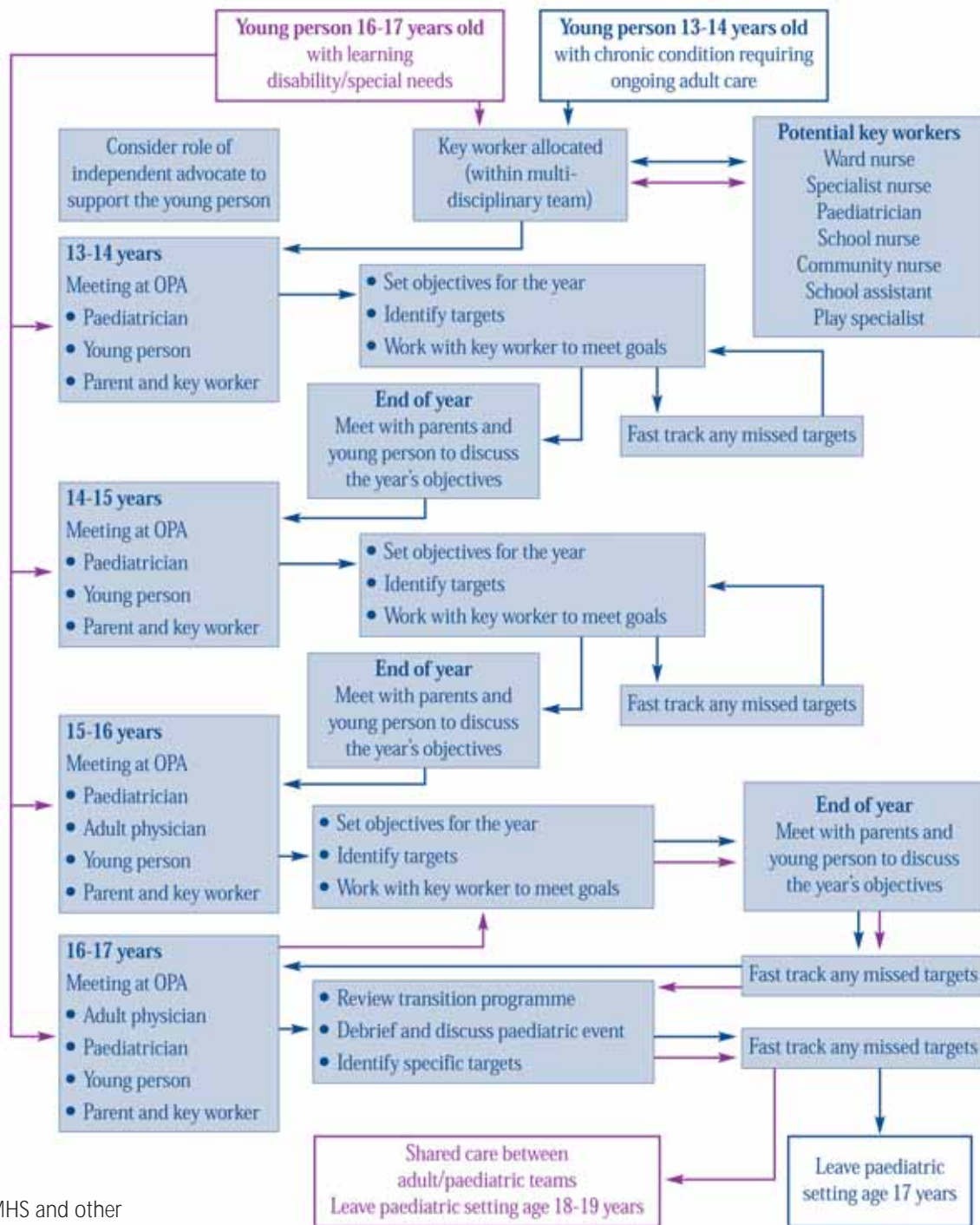
¹ Valuing People: the government's strategy for learning disability in the 21st century, 2000, Department of Health

Resources

Transition: getting it right for young people. Improving the transition of young people with long term conditions from children's to adult health services, 2006, DH

Health Action Plans and Health Facilitation: Good Practice Guidance for Learning Disability Partnership Boards, 2002, DH

2 The RCN clinical pathway for adolescent transition*



* CAMHS and other therapists could be added to this pathway.

Adolescent transition care: Guidance for nursing staff, 2004, Royal College of Nursing www.rcn.org.uk

3 Yorkshire and Humberside Partnership Priority Group on Transition

The Yorkshire and Humberside Partnership 'From Child to Adult' Priority Group provides an active regional focus for improving how young disabled people and their families experience the transition from children's to adult services. Every LA has at least one representative on the group. There are also reps from Health, the voluntary sector, Parent Partnership, CAMHS, LSC, Valuing People, FE, Job Centre Plus, Centre for Learning Excellence, Connexions and Government Office.

The aims of the Group are to develop and share good practice; support the delivery of key areas of policy; and provide intelligence and expertise on issues affecting disabled children and young people at transition, to directly support and inform policy making. The Group is facilitated by two external consultants. It meets quarterly, as do three sub groups on: person-centred transition reviews, families and support for employers. The Group is funded by the Regional Partnership.

Recent and current work (2007/8)

Person-centred transition reviews group

- Sharing good practice on reviews including the work done in Calderdale where education reviewing officers are trained in person-centred transition reviews
- Encouraging local authorities to take advantage of the free training offered by the Valuing People Person-centred Transition Review Programme
- Involvement in a regional conference on transition organised by the Council for Disabled Children, DfES and the Office for Disability Issues with Valuing People.

Support for employers

We are working on:

- Mapping good practice in employment of young disabled people throughout the region
- Finding out what works well
- Information to employers about employing young disabled people, based on the social model of disability
- Expressing the importance of college courses preparing young people with the skills local employers want.

Families

Another sub group is looking at what support families need at transition including relevant, accessible and timely information. An information project involving family members is currently being planned.

What's happening around the region

We are mapping transition work throughout the region as a way of sharing knowledge and contacts. See the website for the latest version at www.thepartnership-yh.org.uk

4 Multi agency pathway from Leicester City

Integrated Pathway for Young People with Learning Difficulties and/or Disabilities for securing Further Education, provision including, Specialist College provision.

*** Year 8**

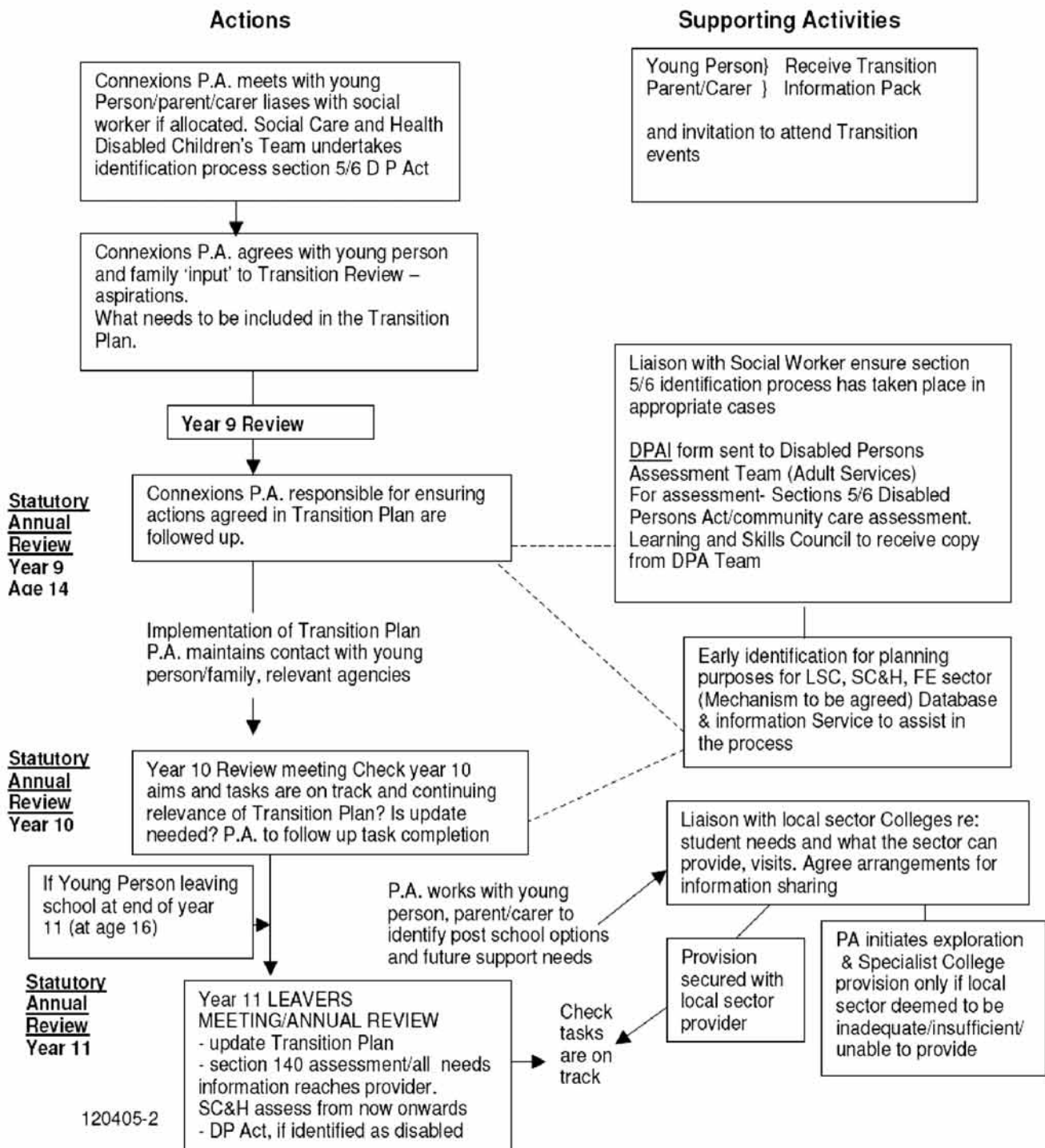
- LEA Informs Connexions Service of young people with statements of Special Educational Needs.
- Connexions starts liaison work with Disabled Children's Team and Child Care Operations Team.

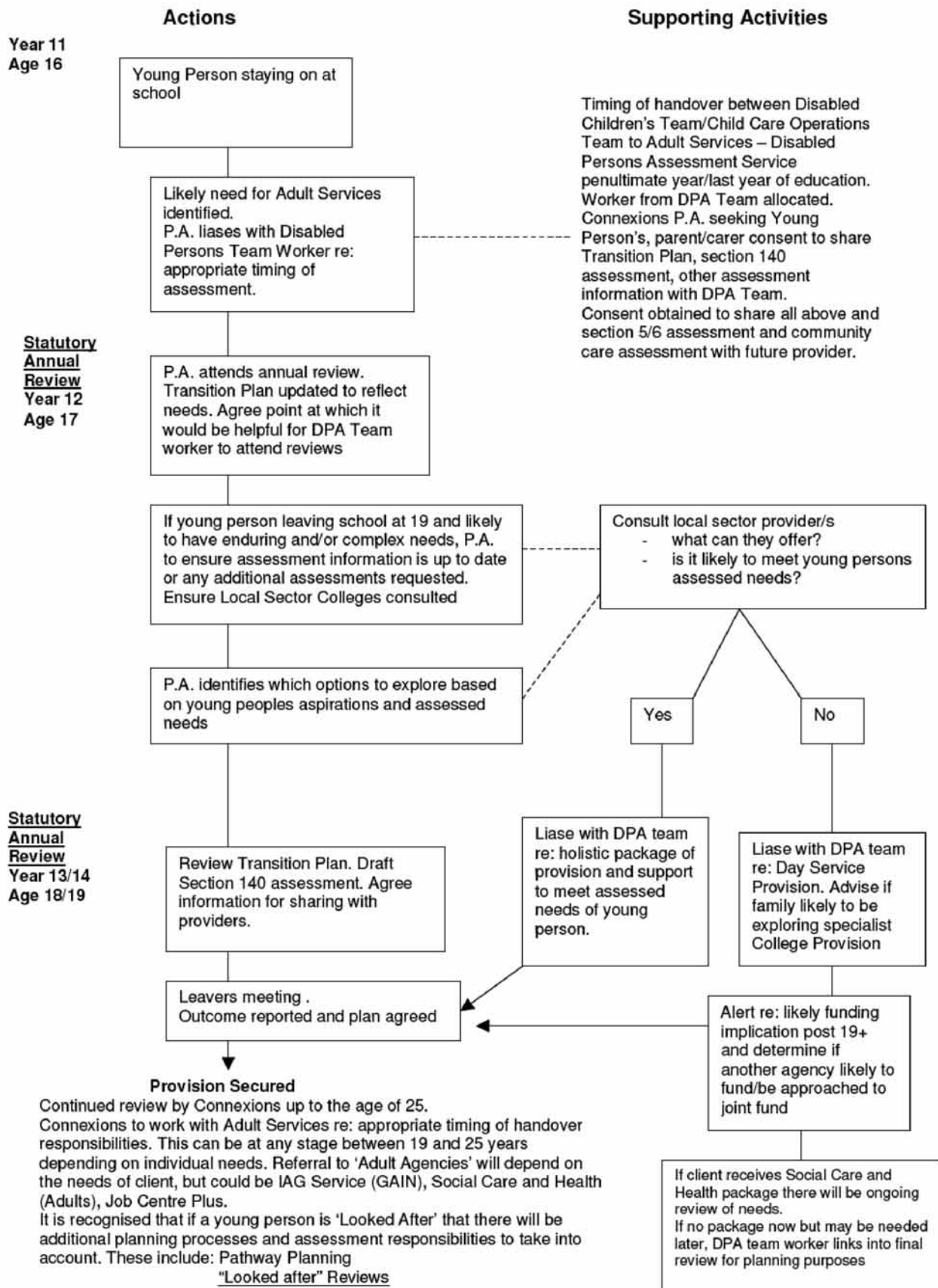
*** Year 9**

- Connexions P.A.

- Receives a copy of statement from LEA
- Attendance at year 9 review compulsory.

- * Each agency to consider how it is to be represented at Statutory Annual Review





Different Professionals link in at different times

5 The Quest – for improved services in Transition to Adulthood in Leicester

Introduction

This article considers the problem of developing interagency transition pathways for disabled and special needs young people. It reviews the nature of the problem and the requirements of parent/carers and young people. The writer looks at the process that has led to an agreed interagency pathway in Leicester. Finally the essay examines some of the future work that is needed.

The mountain – the problem

Transition to adulthood has always been a large mountain, covered in cloud and high winds. (Some would say a good deal of hot air as well!). The mountain, when viewed from different sides leads to various different, appreciations of the geography. This can lead to different routes to the summit. Typically we discovered that, Education, Further Education Colleges, Health and Social Care all had a different appreciation of the topography.

The key issue to resolve such differences was that Parent/Carers and Young disabled adults all made it absolutely clear that we had to climb the mountain – roped together. The aim, therefore, was to agree a pathway up the mountain, to reduce complaints and unnecessary disputes – we had to trust and rely on each other.

Base camp

Having agreed to climb the pinnacle some key elements of the leadership were assembled. The Connexions Senior Manager for Learning Disabilities and Disabilities, the LD Head of Service in Social Services and the Service Manager for Disabled Children agreed to lead the developments.

A series of early (rather than easy) wins were identified. These were smaller, but challenging peaks. The idea was that by working together we would develop mutual trust and confidence as well as a team approach: all would recognise the same initiatives and achievements. Examples of these foothills are:

- Regular transition information events – 14 to date
- Transitions Information Packs that are issued each year
- Commitment to a programme of information sharing

The foothills

We have been surveying this mountain for four years; it is a major climb rather than a ramble. There have been many preparatory milestones. These have included:

- Scoping meetings
- Focus groups
- Stakeholder events

- Parent/carer consultation
- Young People consultation

Camp 2

The above activities led to two major Stakeholder Events. The significance of these was that they combined professionals, parent/carers and young people's interests together. It was crucial that *half* of the people at the events were consumers of the service. It was also significant that they approached the meeting in a professional manner.

At these events outline presentations were given about the commitment to work together and to produce an agreed policy for transition. The consultation for the policy led to hundreds of colleagues expressing views on the relevant issues.

Camp 3

We were then able to produce a working policy document that is called the 'Journey for Life'. This was adopted informally to practice our approach towards the summit. After about eighteen months of informal officer usage, the revised document was presented to the Leicester Federation (Children and young people's Trust); the Learning Disabilities Partnership Board; the Connexions service and the Special Educational Needs Management Team.

After this achievement we needed to wait for more oxygen ...

Camp 4

More oxygen was delivered in the form of the local children's trust with high-level interagency policy support. The Leicester Federation is a generic trust. However their commitment is to prioritise our disabled children's inclusion policy (Jan 04) and agreed a further commitment to implement an interagency pathway for transition.

This commitment was supported by the LDPB with an assurance to establish an interagency Transitions Task Group. It was at this gathering that the need for a Sherpa was identified.

As a result a post was developed for an interagency pathway professional. The Learning and Skills Council fund the post on a time limited basis. The Sherpa is roped to the transitions champion; the LD head of service and is managed on a day-to-day basis by the lead Service Manager for Disabled Children. The work programme meets the agreed shared agenda.

The summit?

As part of our Children's Trust programme of work, we have now achieved a set of agreed interagency transition procedures for both Education and Social Care. These are each supported by the relevant departmental manuals and, for the first time, complement each other.

A new interagency Pathway has also been agreed. This is an inclusive pathway for securing further education provision for all young people with learning difficulties and disabilities. Social Care Management Team and the LDPB Task Group have adopted it. Also the pathway has been approved by the Connexions service as a key practice standard for all Personal Advisers. Both key partnership bodies are currently accepting the procedure and pathway and there is a commitment to implement interagency training on each aspect of this work.

New horizon ...

We are now completing an interagency protocol that will offer strategic and operational support for a range of services. This protocol is built on the success of this transitions work. It sets out to expand the partnerships and good practice identified in transition into other areas of practice.

As a result our commitment to interagency training will be programmed with shared outcomes that relate to the ECM outcomes and the Valuing People principles. It will support a new brokerage role identified for Personal Advisers, reduce gaps and duplication and, ultimately, revise and simplify the new pathway.

Conclusion

We have climbed the mountain! It is clear that we have made a start. We are gratified that so many agencies believe that they have achieved a shared success. Despite this our future work will ensure that we implement the pathway over the next few months and review its effectiveness in a year.

Parent/Carers and Young People have been involved in developing this service. They will be involved in the training and future improvements.

We have already identified the next challenging summit...

Christopher Bush
Former Service Manager
Disabled Children's Developments
Leicester Federation

APPENDIX 5

Post-16 benefits and education funding

Post-16 benefits

Disabled young people approaching adulthood are likely to need a review of benefits they may be entitled to. This is a complex area and often claiming one benefit or receiving one grant can affect either the combined family income or the young persons ability to work or attend college.

Many agencies working with disabled young people do not offer advice and support on claiming benefits but it is important that staff working with disabled young people and their families know of local agencies who can help. This can be particularly important for young people who have non-verbal communication, learning difficulties or who have English as a second language. Disabled young people and their families may be able to get support when applying for benefits from key workers, the adult social care team or local welfare rights services.

The most common benefits disabled young people may be eligible for are listed below.

Incapacity Benefit

This benefit is currently under government review. Further information can be found at www.jobcentreplus.org.uk

Income Support

Disabled people can claim income support from the age of 16, subject to certain conditions. It can be claimed whether the young person is at work or studying on a full or part time basis (subject to the type of course the learner wishes to pursue post 16 and whether the learner is on an advanced or non-advanced course). For more information: www.jobcentreplus.gov.uk

Disability Living Allowance

is paid to people who have care or mobility needs whether or not they are capable of work, or are working or studying. Disability Living Allowance can also lead to the 'disability premium' which increases the Income Support a learner can be paid and means that they can get Income Support as a full-time student. For more information: www.jobcentreplus.gov.uk

Community Care Grants

Can be paid to people who get Income Support, to help with their expenses. There is also a sum of money that may help young people move to their into their own home. For more information: www.jobcentreplus.gov.uk

Working Tax Credit

This benefit is designed for people on low income and who work at least 16 hours a week. Eligibility criteria apply. For more information: www.jobcentreplus.gov.uk

Education Maintenance Allowance (EMA)

Students can claim an allowance (£30 per week at the moment) to help with costs of books, travel and equipment. For more information: www.lsc.gov.uk

Disabled Student Allowances (DSA)

Young disabled people who go on to higher education may be eligible for DSA. The disabled students allowance is available to students who incur course related expenditure due to their disability. There are additional allowances to help disabled students:

- Non medical personal helper
- Major items of specialist equipment
- Other expenditure

For more information: www.direct.gov.uk and www.skill.org.uk

Funding for post-16 education

Local further education (FE) colleges, sixth forms (school and colleges) and work based learning (WBL) in England are funded by the Learning and Skills Council (LSC). Some providers may also receive local authority funding. The LSC has a duty to fund specialist places for students under the age of 19 whose needs cannot be met by a mainstream FE college and may also fund a specialist place for students between the ages of 19–25 whose needs cannot be met elsewhere.

Where it is set out in the young person's transition plan, local authorities should fund places for students between the ages of 16–19. Separate funding is available for FE providers in England to pay for Additional Learning Support (ALS) needed by disabled students. This support is defined as: *'any activity that provides direct support for learning to individual learners, over and above that which is normally provided in a standard learning programme that leads to their learning goal'*.¹

It can be used for things such as additional teaching for dyslexic students, an interpreter for deaf students, materials in alternative formats or specialist computer software.

Additional funding that may be available includes:

- **Education Maintenance Allowances (EMAs)** The EMA is a weekly allowance that aims to encourage more young people to stay in FE once their compulsory schooling ends.
- **Learner Support Funds** These funds are available from the FE provider to help with variable expenses such as transport costs, books, and accommodation costs if learners take a course that is a considerable distance from home.
- **Access/Hardship Funds** These funds are to help individuals to engage in or remain on FE courses by providing financial assistance.

For further information: www.lsc.gov.uk

¹ Funding Guidance for Further Education in 2004/05 Learning and Skills Council (2004)

Quality standard checklists

Chapter 1 The transition process

Developing a strategic transition protocol

A1. Quality standards – developing a transition protocol

<i>Lead body</i>	<i>Action</i>	
Children and Young People's Strategic Partnership Board (CYPSPB)	Set out local commitment to developing a multi-agency transition protocol	<input type="checkbox"/>
CYPSPB	Designate work on this to a specific group	<input type="checkbox"/>
CYPSPB	Set out commitment to this process in the Children and Young People's Plan (CYPP)	<input type="checkbox"/>
CYPSPB and Learning Disability Partnership Board (LDPB)	Set up a transitions subgroup to develop the protocol	<input type="checkbox"/>
Multi-agency transition group	Members from all key agencies who have the power to make decisions and sign up to providing particular services	<input type="checkbox"/>
Multi-agency transition group	Arrange for the views of disabled young people and their families to inform the development of the protocol	<input type="checkbox"/>

A2. Developing a transition protocol – local area checklist

<i>Information</i>	<i>Current arrangement</i>	<i>What further work is needed? Who is the lead person?</i>
Does the Children and Young People's Plan (CYPP) list a commitment to develop a multi-agency transition protocol?	yes/no	
Is there a transition group made up of staff with the power to sign up to a protocol on behalf of their agency?	yes/no	
Does the draft protocol set out what local services will do – as well as what they must do?	yes/no	
Who is responsible for publishing and distributing the final protocol?	yes/no	
Are all agencies signed up to the protocol?	yes/no	

Developing a local transition pathway

A3. Quality standards – developing a transition pathway

<i>Lead body</i>	<i>Action</i>	
Multi-agency transition group	Develop a clear operational plan to implement the transition protocol	<input type="checkbox"/>
Multi-agency transition group	Oversee the process of implementation with agreed responsibilities allocated to agencies like children's services and Connexions	<input type="checkbox"/>
Multi-agency transition group	Make arrangements to evaluate transition process	<input type="checkbox"/>
Multi-agency transition group	Review how disabled young people are involved in planning improvements to services	<input type="checkbox"/>
Multi-agency transition group	Make time to have disabled young people and their families share their views on how services can be improved	<input type="checkbox"/>
Multi-agency transition group	Group membership to include transport, housing and leisure services	<input type="checkbox"/>
Children and Young People's Strategic Partnership Board (CYSPB)	Ensure multi-agency transition group have opportunities to meet and have enough time to implement change effectively	<input type="checkbox"/>
CYSPB	Ensure the multi-agency transition group members have the authority to make decisions and take actions forward from the group	<input type="checkbox"/>

A4. Developing a transition pathway – multi agency transition group

<i>Information</i>	<i>Current arrangement</i>	<i>What further work is needed? Who is the lead person?</i>
Is there an established multi agency transition group?	yes/no	
Are the following agencies and individuals represented:		
• Disabled young people	yes/no	
• Families	yes/no	
• Children's social care	yes/no	
• Adults social care	yes/no	
• Education at LA	yes/no	
• Education – individual mainstream schools	yes/no	
• Education – special schools	yes/no	
• Connexions/Careers service	yes/no	
• PCT	yes/no	
• Acute health services and primary care	yes/no	
• Community health services e.g. nursing, therapies	yes/no	
• CAMHS services	yes/no	
• Transport	yes/no	
• Housing	yes/no	
• Colleges	yes/no	
• Job centre plus	yes/no	
• Leisure services	yes/no	
Do other agencies link into this group for advice? E.g. local authority planning department, commissioning team or training department.	yes/no	

A5. Developing a transition pathway – transition group actions

<i>Information</i>	<i>Current arrangement</i>	<i>What further work is needed? Who is the lead person?</i>
Does the multi-agency transition group have a protocol to work with?	yes/no	
Were they involved in developing it?	yes/no	
Do key members of the group meet regularly, at least every 2-3 months?	yes/no	
Do all group members meet at least twice a year?	yes/no	
Is there a nominated 'Transition Champion' in the group?	yes/no	
Does the group have a clear role in developing/ implementing the transition pathway?	yes/no	
Are disabled young people and families supported to participate in the group?	yes/no	

Transition reviews

A6. Quality standards – effective transition reviews

<i>Lead body</i>	<i>Action</i>	
Children and Young People's Strategic Partnership Board (CYPSPB)	Set out commitment to improving the local review process	<input type="checkbox"/>
Multi-agency transition group (MATG)	Gather disabled young peoples views on the current arrangements and draw up action plan to improve. The number of agencies involved in the lives of young people who are looked after means this is especially important for this group.	<input type="checkbox"/>
MATG	Encourages and monitors use of joint assessments	<input type="checkbox"/>
Local authority training department	Work with the MATG and agencies to develop joint training for staff groups to enhance understanding of roles and raise awareness of disability equality.	<input type="checkbox"/>

A7. Effective transition reviews – input from disabled young people and families/carers

<i>Action</i>	<i>Date to be completed by</i>	<i>What further work is needed? Who is the lead person?</i>
Identify the professional who will be working with the young person to prepare for the review		
Meet with young person to draw up list of people to invite		
Check best times for young person and family		
Young person to decide whether or not they want to attend		
List support young person would like to have at the meeting		
Check with family/carers what support they will need at the meeting		
Check with young person and family/carers what support they would like to help them prepare for the meeting		
Everyone knows who is organising the meeting		
Everyone knows who is responsible for taking action after the meeting		
Agree on possible venues with young person		
If not young person's choice: do access audit of meeting space with any access needs they have in mind		
Order drinks and snacks		
Book interpreters if needed		
Ask all staff attending to write a paragraph on their job to send out with the papers before the meeting		
Send out papers to everyone in good time		
Identify a contact person for queries about the meeting		

A8. Effective transition reviews – practitioner’s checklist

<i>Action</i>	<i>Date to be completed by</i>	<i>What further work is needed? Who is the lead person?</i>
Information from assessments brought together for the review and shared with other agencies		
Submit reports well before the meeting		
Use existing appointments to discuss report with young person beforehand		
Make sure reports are updated before each annual review		
Make times to meet with the young person and their family both together and separately		
Make time to get to know the young person and gain their confidence to better support them to represent their needs and wishes at the review and throughout the transition process		

A9. Effective transition reviews – local authority SEN officer

<i>Action</i>	<i>Date to be completed by</i>	<i>What further work is needed? Who is the lead person?</i>
Information on all young people in the area who need a transition review during the next school year, including young people who are home tutored, in a pupil referral unit or in hospital, must be sent to schools, Connexions and other agencies (e.g. children’s home; responsible local authority team manager if the child is looked after) in plenty of time		
Write to parents/carers and relevant professionals to inform them of local authority decisions following the review		
The key worker or named person must contact the young person and inform them of local authority decisions following the review		

A10. Effective transition reviews – health staff providing input to the review

<i>Action</i>	<i>Date to be completed by</i>	<i>What further work is needed? Who is the lead person?</i>
Discuss transition review with young person at appointments		
Provide written information to review meeting – and share with young person and family/carer beforehand		
Attend Year 9 review where possible		
Discuss specific transition to adult health services with young person and family in good time		
Provide information on all new clinics which the young person is likely to attend		
Work with colleagues to provide a handover of files and information in good time		
Arrange visits to new clinics before the transfer with the young person		
Keep GP informed of process		
Contribute to developing health action plans at Year 9 for all disabled young people/ensure that the individual health plan for a looked after child is kept up to date.		

A11. Effective transition reviews – after the meeting

<i>Action</i>	<i>Date to be completed by</i>	<i>What further work is needed? Who is the lead person?</i>
Note-taker to distribute draft minutes for approval		
Agreed lead person needs to go through the minutes and proposed action in detail with young person and family/carer		
Once action has been agreed, notify LSC of potential funding need in future		
Collect each agency's action plan on how they will implement the agreed actions. Forward to all		
Agreed lead person needs to oversee the making of a transition plan and monitor it. This person needs to have an understanding of the needs of disabled children		
Agreed lead person double-check that young person and family/carer are happy with the meeting's outcomes		

A12. Effective transition reviews (children in care) – input from social worker/personal adviser

<i>Action</i>	<i>Date to be completed by</i>	<i>What further work is needed? Who is the lead person?</i>
Consult with social worker/personal adviser/designated teacher as appropriate about young person's needs as early as possible		
Attend a care planning/ pathway planning review [in Years 9, 10 and 11] where possible		
Ensure that agreed actions about supporting education and living arrangements from transition review are reflected in care planning processes		

Post-16 options: education and employment

A13. Quality standards – developing local choice and opportunity

<i>Lead body</i>	<i>Action</i>	
Children and Young People's Strategic Partnership Board	State links with local colleges and support for learning opportunities for all	<input type="checkbox"/>
Learning and Skills Council	Links with local colleges and support to offer quick and suitable support to disabled students	<input type="checkbox"/>
Multi-agency transition group	Membership of local colleges	<input type="checkbox"/>
Transition Champion	Promote range of post 16 options and encourage agencies to discuss with disabled young people they work with	<input type="checkbox"/>
Transition Review Coordinator	Ensure post 16 options are part of every transition review	<input type="checkbox"/>
Connexions/Careers agency/LSC and Job Centre Plus	Work with local employers to create work experience placements, work opportunities for disabled young people with a range of needs	<input type="checkbox"/>

A14. Person-centred approaches

<i>Lead body</i>	<i>Action</i>	
Children and Young People's Strategic Partnership Board	Commitment to use person-centred approaches in all assessments with children and young people.	<input type="checkbox"/>
Multi-agency transition group (MATG)	Develop a strategy across agencies to extend the use of person-centred planning to all transition reviews and processes.	<input type="checkbox"/>
MATG	Develop a strategy with partners so all key staff have training in using person-centred approaches	<input type="checkbox"/>

Chapter 2 Statutory services – an overview

Children’s trust models and multi-agency working in the transition process

B1. Quality standards – multi-agency working at transition

<i>Lead body</i>	<i>Action</i>	
Children and Young People’s Strategic Partnership Board (CYPSPB) and the children’s trust board	Endorse work on developing a transition protocol and improving transition services. Allocate resources to support specific activity	<input type="checkbox"/>
CYPSPB	Agree lead agency to coordinate actions to improve services and support available to disabled young people at transition	<input type="checkbox"/>
Children and Young People’s Plan, (CYPP)	States as an aim excellent transition support services for disabled young people from mainstream and specialist services.	<input type="checkbox"/>
CYPP or further operational document supporting CYPP	States how young people will be involved in service planning, specifically disabled young people – in particular those from black and other minority ethnic groups and those ‘looked after’ by the local authority.	<input type="checkbox"/>
CYPP	States young people should be at heart of service planning	<input type="checkbox"/>
CYPP – detail	States who leads on this work, what specific service aims are for disabled young people, those with statements or on School Action and School Action Plus	<input type="checkbox"/>
Local authority Disability Equality Scheme (DES) (or appropriate sub-schemes)	State how services at transition will improve disabled young people’s participation in decision making and service planning	<input type="checkbox"/>
Local authority DES (or appropriate sub-schemes)	State which disabled young people will be consulted as representatives of the local population	<input type="checkbox"/>
Transition Champion/Learning Disability Partnership Board	Make links with local Parent Partnership service and parents groups to gather views to inform service improvement	<input type="checkbox"/>
All agencies	Make a joint statement committing to developing a multi-agency transition protocol and working together to produce it.	<input type="checkbox"/>
All agencies	Sign up to a shared aim of promoting the rights of disabled children and supporting them to reach their full potential.	<input type="checkbox"/>
Lead member with responsibility for children’s services	Champion transition issues	<input type="checkbox"/>

B2. Multi agency working at transition – local area checklist

<i>Information</i>	<i>Current arrangement</i>	<i>What further work is needed? Who is the lead person?</i>
Is transition planning covered in the CYPP?	yes/no	
Is there a separate strand on how to achieve local outcomes in transition for all disabled young people including those on School Action and School Action Plus?	yes/no	
Has there been agreement on which agency will lead the transition process?	yes/no	
Who is the strategic champion for this work?		
How are disabled young people and their families involved in strategic planning?		
Is there agreement across agencies on which young people need support and from where?	yes/no	
How do agencies joint plan to ensure there are no gaps in support as young people make the transition into adult social care and health services?		
How is data from across services collected and used to support the transition process?		
Is there clear local guidance on which agencies should be involved in this process – for example, Connexions/IAG provider, LSC, local colleges, PCTs, etc?	yes/no	
Is the Learning Disability Partnership Board Transition Champion involved in the process?	yes/no	
Have there been cross-agency training/joint working days to give people a better idea of what everyone does or is responsible for?	yes/no	
Are any changes to working structures clearly explained to all? Are the benefits clear – e.g. better outcomes for all disabled young people?	yes/no	

Education – schools in strategic planning

B3. Quality standards – schools in strategic planning

<i>Lead body</i>	<i>Action</i>	
Children and Young People's Strategic Partnership Board	Along with the director of children's services, who represents education on the board and who represents individual schools? How is information disseminated across school clusters on decisions and issues at the board?	<input type="checkbox"/>
School clusters	Work with children's trust on service commissioning, for example, speech and language therapy and physiotherapy services to ensure equitable provision for all disabled young people	<input type="checkbox"/>
School clusters	Make arrangements to share learning and effective practice across the cluster	<input type="checkbox"/>
SENCOs	Meet regularly to update on policy and practice issues and share learning, arrange joint training for staff, etc	<input type="checkbox"/>
Individual schools	Have clear agreements with local IAG/Connexions services on arrangements for supporting disabled young people from the Year 9 transition review	<input type="checkbox"/>
Individual schools	Have a statement and support plan for including disabled young people in their transition planning	<input type="checkbox"/>
Individual schools and clusters	Develop an evaluation system to periodically review the transition planning arrangements and how they can be improved	<input type="checkbox"/>

B4. Schools in strategic planning – local area checklist

<i>Information</i>	<i>Date to be completed by</i>	<i>What further work is needed? Who is the lead person?</i>
Who is responsible locally for collating information on all children who will need a transition review, compiling it and sending it to all relevant parties?		
Who leads developments in transition planning for the school cluster?		
How does the school and school cluster work with the children's trust on planning?		
How do schools work with the local children's trust to ensure equitable spread of provision, for example speech and language therapists, to support disabled young people at transition?		
How often do SENCOs meet to review practice in transition planning?		
Is there a written agreement for each school with the IAG/Connexions service to support disabled young people?		
Does each school have a clear protocol on who is responsible for coordinating actions on transition arrangements for pupils?		
Does each school have a participation policy for young people which is applied to the transition process?		
Is any regular evaluation of the transition planning process in place in schools?		

Social care services – strategy and structure

B5. Quality standards – children and adult social care at transition

<i>Lead body</i>	<i>Action</i>	
Director of children's services	Champions transition issues at CYPSPB	<input type="checkbox"/>
Director of adults social care services	Champions transition issues at CYPSPB	<input type="checkbox"/>
Lead member with responsibility for children's services	Champions transition issues	<input type="checkbox"/>
Directors of children's and adult services	Agree joint social care approach to transition Take lead role in transition subgroup Work with colleagues in health, Connexions, school clusters, etc to agree draft transition protocol	<input type="checkbox"/>

B6. Children and adult social care at transition – local area checklist

<i>Information</i>	<i>Current arrangement</i>	<i>What further work is needed? Who is the lead person?</i>
Do strategic planning staff and directors of children's and adult services understand the roles, priorities and culture of other agencies such as health, education, Connexions, other agencies – youth service, housing, transport?	yes/no	
Has a multi-agency transition protocol been developed with partner agencies?	yes/no	
Is there a separate protocol or section in the main protocol describing support for disabled young people who are placed out of authority and for looked after children who are out of school?	yes/no	
Is there agreement between adult and children's services about when the numbers of young people known to be moving into adult services will be sent from one service to the other? Are these figures shared and compared with health and education services?	yes/no	
Are transition services evaluated?	yes/no	
How can disabled young people and their families contribute to this?	yes/no	
Is there joint work on strategies to support disabled young people from black and minority ethnic communities?	yes/no	
Is transition planning shared with relevant practitioners in other agencies so that an integrated transition plan can be developed?	yes/no	

Health services

B7. Strategic planning of transition services in health¹

<i>Information</i>	<i>Date to be completed by</i>	<i>What further work is needed? Who is the lead person?</i>
Address professional and managerial attitudes.		
Recognise that transition is a process, not an event.		
Recognise the differing perspectives of paediatricians, physicians and GPs, and other health professionals.		
Establish dialogue between clinicians, management and commissioners and other agencies.		
Develop an appropriate environment for adolescents (adapting existing facilities as appropriate).		
Consult with users – e.g. young people and their parents.		
Agree a policy on the timing of transition. The exact time of transfer should depend on an individual's readiness and needs.		
Set up a preparation period and education programme for the young person and parent. Identify the necessary skill-set to enable the young person to access and make full use of adult services.		
Plan a coordinated transfer process; this depends on the model of care used locally.		
Identify interested and capable adult services.		
Identify a coordinator – someone to coordinate care when young person receives input from different consultant teams and health professionals.		
Consider information transfer.		
Set up monitoring and fail-safe mechanisms to ensure that young people are attending the adult clinic.		
Ensure primary care involvement.		
Negotiate administrative support.		

¹ From: *Transition: getting it right for young people. Improving the transition of young people with long term conditions from children's to adult health services*, 2006, DH and DfES

The following points have been taken from a number of papers which have been written by health professionals keen to see improved support for disabled young people who are making the transition from child to adult health services.²

B8.

<i>Information</i>	<i>Date to be completed by</i>	<i>What further work is needed? Who is the lead person?</i>
Is there a written policy?		
Is there a preparation period and education programme with an individualised approach that addresses psychosocial and educational/vocational needs, provides opportunities for adolescents to express opinions and make informed decisions, and gives them the option of being seen by professionals without their parents?		
Is there the involvement of a team of health professionals as required by the young person's identified needs?		
Is there a coordinated transition process with a named coordinator and continuity in health personnel when possible?		
Is there an interested and capable adult clinical service?		
Administrative support in place?		
Primary health care and social care involvement?		

B9. Health services at transition – local area checklist

<i>Information</i>	<i>Date to be completed by</i>	<i>What further work is needed? Who is the lead person?</i>
Who represents primary care services on the CYPSPB?		
Who is representing health services in developing the local multi-agency transition protocol?		
Who is leading from health services in drawing up the multi-agency transition map for provision of local services?		
How are all health staff working with individual disabled young people informed of arrangements for transition and when they should start?		

2 From: Viner R M, 'Transition from paediatric to adult care. Bridging the gaps or passing the buck?', *Arch Dis Child* 1999, 81, pp 271-75.; Shaw K L, Southwood T R, McDonagh J E, 'Transitional care for adolescents with juvenile idiopathic arthritis: results of a Delphi Study', *Rheumatology* 2004, 43, pp 1000-06; McDonagh J E, 'Growing up and moving on. Transition from paediatric to adult care', *Paediatric Transplantation* 2005

Connexions, information advice and guidance professionals

B10. Quality standards – strategic planning, Connexions and IAG arrangements

<i>Lead body</i>	<i>Action</i>	
Connexions/IAG provider/management	• Role on CYPSPB	<input type="checkbox"/>
	• Role in developing children and young people's plan	<input type="checkbox"/>
	• Role in developing specific transition protocol	<input type="checkbox"/>
	• Agreements with all schools on support arrangements for disabled young people at transition	<input type="checkbox"/>
	• Work with other services – including the Children's Information Service – to develop information and resources on post-16 options	<input type="checkbox"/>
	• Clear communication with LSC where needed	<input type="checkbox"/>
	• Work with Jobcentre Plus on how to jointly support disabled young people	<input type="checkbox"/>

B11. Connexions and IAG arrangements – local area checklist

<i>Information</i>	<i>Current arrangement</i>	<i>What further work is needed? Who is the lead person?</i>
Does Connexions have an up-to-date record of all young people in Year 8 with SEN and those on School Action and School Action Plus?	yes/no	
Are all of these young people allocated a personal adviser?	yes/no	
Is there a lead person in IAG/Connexions with strategic responsibility for developing support for disabled young people?	yes/no	
Is there a lead person for links to colleges developing courses and support for disabled young people?	yes/no	
Is there an agreement across agencies about how Section 140 assessment fits with other assessment requirements at transition?	yes/no	
Are dates fixed for Year 9 Review in good time with young person, families and other agencies?	yes/no	

Chapter 3 Participation and further support

Participation of disabled young people in the transition process

Participation of families in the transition process

Checklist for preparing effective transition reviews with input from disabled young people and their families/carers can be found in the transition review section, page 117 of this appendix.

C1. Supporting disabled young people and their families – key workers and lead professionals

<i>Action</i>	<i>Date to be completed by</i>	<i>What further work is needed? Who is the lead person?</i>
Promote the status of key worker/lead professional across agencies to make sure they have the authority to negotiate on a family's behalf.		
Involve disabled young people and families in choosing their key worker.		
Involve families in recruiting key workers and planning for who takes on lead professional roles.		
Be clear how the work is funded and accommodated in existing workloads.		

Supporting disabled young people and their families: direct payments and individual budgets

C2. Quality standards – strategic planning for direct payments and individual budgets

<i>Lead body</i>	<i>Action</i>	
Multi Agency Transition Group (MATG)	<ul style="list-style-type: none"> Gather views of families and disabled young people on: uptake of direct payments Demand for individual budgets 	<input type="checkbox"/>
Children's services department	<ul style="list-style-type: none"> Implement direct payments scheme Monitor and assess effectiveness of direct payments scheme 	<input type="checkbox"/>
Local authority/Children and Young People Strategic Partnership Board	Work with partner agencies to develop local workforce to meet demand from families organising their own support	<input type="checkbox"/>
Director of children's services/director of adult services	Review short breaks and direct payment policies and criteria so it is easier for disabled young people to use this support to access formal and informal youth service initiatives.	<input type="checkbox"/>

C3. Providing direct payments³ – children’s services department

<i>Information</i>	<i>Current arrangement</i>	<i>What further work is needed? Who is the lead person?</i>
Is a direct payments scheme in place in the local authority for families and 16–17 year olds?	yes/no	
Is there a named person in children’s services who can support families wanting more information?	yes/no	
Are staff supporting families able to advise on what direct payments can be used for and how these criteria can be used flexibly?	yes/no	
Do staff supporting families to apply understand the criteria, local cost of support and likely availability of that support for families?	yes/no	
Is there provision made to support families with becoming employers if they chose to?	yes/no	

Information for disabled young people and their families about the transition process

C4. Quality standards – planning a transition pack

<i>Lead body</i>	<i>Action</i>	
Multi-agency transition group	• Identify lead agency to develop the guide	<input type="checkbox"/>
	• Identify local families group and disabled young people to work with in developing the pack, including families from black and minority ethnic groups	<input type="checkbox"/>
	• Identify a lead agency to coordinate funds to produce and disseminate the pack locally, and cover future update costs	<input type="checkbox"/>
	• Identify a lead person to coordinate the work	<input type="checkbox"/>
	• Review current pack/research packs from other areas	<input type="checkbox"/>
	• Double check agreement with all agencies on their roles and responsibilities set out in the pack	<input type="checkbox"/>
	• Have the final version available in a range of accessible formats	<input type="checkbox"/>

³ Health and Social Care Act 2001

C5. Developing a transition pack – access and maintenance

<i>Information</i>	<i>Current arrangement</i>	<i>What further work is needed? Who is the lead person?</i>
Is the pack available from a range of services?	yes/no	
Is it on a website?	yes/no	
Is it in paper copies?	yes/no	
Is it available in a range of languages and formats?	yes/no	
Is there an identified person/agency responsible for cross checking information and updating the pack?	yes/no	
Is the local children's information service (CIS) aware of the pack?	yes/no	
Can the CIS offer further information e.g. do they know where to refer people to?	yes/no	
Are families and disabled young people being asked to comment on the content and what is useful/not useful?	yes/no	

Leisure services

C6. Quality standards – planning improved access in play and leisure settings

<i>Lead body</i>	<i>Action</i>	
CYPSPB and local leisure services	Set out existing and planned support for improved access and inclusion at local resources	<input type="checkbox"/>
Director of children's services/director of adult services	Review short break and direct payment policies and criteria to make it easier for disabled young people to use these to access formal and informal leisure opportunities	<input type="checkbox"/>
Lead member and council	Integrate views of disabled young people into plans for long-term building and improvements	<input type="checkbox"/>

C7. Planning improved access – local areas checklist for leisure services

<i>Information</i>	<i>Current arrangement</i>	<i>What further work is needed? Who is the lead person?</i>
Does the service have eligibility criteria? For example, is a certain level of fitness required?	yes/no	
Are the eligibility criteria fair and equitable – e.g., is there some flexibility to accommodate individual needs within reason?	yes/no	
Is there a risk management policy in place to guide considerations of individual cases?	yes/no	
Is information available on the local population of disabled children, e.g. through links with families, local community groups?	yes/no	
Are disabled young people involved in consultations about service development?	yes/no	
Is information provided in a range of formats?	yes/no	
Does publicity for and information about the service contain positive, inclusive images and language?	yes/no	
Do staff have comprehensive disability equality training?	yes/no	
Are staff able to demonstrate how standard activities and equipment can be adapted for disabled young people with a range of impairments?	yes/no	

Youth services and activities

C8. Quality standards – access and inclusion in locally commissioned activities for young people

<i>Lead body</i>	<i>Action</i>	
CYPSPB and local youth services	Set out existing and planned support for improved access and inclusion at local settings	<input type="checkbox"/>
Director of children's services/director of adult services	Review short break and direct payment policies and criteria to make it easier for disabled young people to use this support to access formal and informal youth service initiatives	<input type="checkbox"/>
Lead member and council	Integrate views of disabled young people into plans for long-term building and improvements to youth and activity centres	<input type="checkbox"/>

C9. Access and inclusion planning for youth and activity providers

<i>Information</i>	<i>Current arrangement</i>	<i>What further work is needed? Who is the lead person?</i>
Is the setting able to adapt access and activities to meet the needs of disabled young people with a range of impairments?	yes/no	
Is a risk management policy in place to guide considerations of individual cases?	yes/no	
Is information available on the local population of disabled children – e.g. through links with families, local community groups?	yes/no	
Are disabled young people, including those from black and minority ethnic groups involved in consultations about service development?	yes/no	
Does publicity for and information about the service contain positive, inclusive images and language?	yes/no	
Do staff have disability equality training?	yes/no	
Is information available in a range of formats?	yes/no	

Transport

C10. Quality standards – access to transport services

<i>Lead body</i>	<i>Action</i>	
Children and Young Peoples Strategic Partnership Board (CYPSPB) /lead member/council	Work on providing safe, accessible, public transport	<input type="checkbox"/>
CYPSPB	Review transport provision for young people, gather their views on what needs to change and develop strategy	<input type="checkbox"/>
Multi Agency Transition Group (MATG)	Work with partners to look at current provision for disabled young people and what could be improved. Feed into CYPSPB strategy	<input type="checkbox"/>
MATG	Work with member agencies to ensure transport is a consideration in all planning and development of support and services	<input type="checkbox"/>

C11. Access to transport – assessment processes and planning

<i>Information</i>	<i>Current arrangement</i>	<i>What further work is needed? Who is the lead person?</i>
Is access to suitable transport considered as a key part of planning in:		
Transition reviews	yes/no	
Family support arrangements	yes/no	
Play schemes	yes/no	
Extended school activities	yes/no	
Youth services	yes/no	
APIR assessment	yes/no	
College assessments	yes/no	
Are transport providers consulted or included in review processes or new service plans?	yes/no	
Is the local transport budget regularly reviewed to assess how effectively needs are being met?	yes/no	

The transition from school to adulthood is a time of celebration, change and challenges for all young people. They will be considering and making decisions about their career, their continuing education, their social life and where they will live. For many disabled young people and those with special educational needs having access to timely and comprehensive information, advice and guidance can be enough to help them reach their goals. For others, more support may be needed from a range of services to enable them to reach their full potential.

Currently, support available locally for disabled young people and their families varies widely. Services are struggling to provide timely support, share expertise and work together effectively to support this group of young people. It is essential that joined-up and comprehensive services are available throughout the transition process that will enable disabled young people to grow up and live the lives they want, to fully participate and be active members of their community.

This guide brings together all key information for professionals about the transition process. It includes information on statutory duties and offers examples of effective practice to illustrate how services are addressing local need. It contains checklists, which offer information on meeting key obligations and providing minimum quality standards, to support agencies in providing a framework of services to effectively meet the needs of disabled young people in their transition to adulthood.

This guide is a starting point to give all services useful information and examples of excellent support for disabled young people and their families.

Updates, further case studies and resources will be available on www.transitioninfonyetwork.org.uk.

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You can download this guide from www.everychildmatters.gov.uk and www.transitioninfonyetwork.org.uk.

Copies of this publication can also be obtained from:

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