Making the transition: Addressing barriers in services for disabled people

Ini Grewal, Sally McManus, Sue Arthur with Lorna Reith

A report of research carried out by the National Centre for Social Research with the Disability Alliance on behalf of the Department for Work and Pensions
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We would like to thank everybody who participated in this study. In particular we are indebted to the disabled people who gave freely of their time to take part in this research and who shared with us their experiences of service use and transitions. We are also grateful to the service providers and policy officials who agreed to be interviewed and to the disability organisations that helped with the recruitment of the disabled people.

We have been ably supported and advised throughout the project by two reference groups, one consisting of representatives of disability organisations and the other made up of Government policy officials. We would also like to thank our research managers, Claire Edwards and Grahame Whitfield from DWP's Social Research Division, Sue Green from the Disability Unit at DWP and the Disability Rights Commission for their input to the steering group.

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# Glossary of terms and abbreviations

**Note**

The glossary refers to terms as they are used in the context of this report.

Some of these definitions and links draw on those that can be found on the Guardian newspaper’s Society website. [http://society.guardian.co.uk/glossary/](http://society.guardian.co.uk/glossary/)

<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Access</td>
<td>The extent to which service users are able to receive the care they require. The issues involved in accessibility include travelling, physical access (e.g. whether premises are suitable for wheelchairs), and communication (e.g. interpreters). <a href="http://www.doh.gov.uk/scg/facs/index.htm">http://www.doh.gov.uk/scg/facs/index.htm</a></td>
</tr>
<tr>
<td>Advocacy</td>
<td>Advocates support and argue the case for a service user or help them to put across their point of view. They are usually employed in social care to support disadvantaged groups, including some disabled people.</td>
</tr>
<tr>
<td>Assessment</td>
<td>(1) Measuring the circumstances of an individual (or family) against one or more benchmarks in relation to making a plan of action (or diagnosis). (2) Inquiring into the financial resources of an individual or family to determine whether they should make a contribution towards a service.</td>
</tr>
<tr>
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</tr>
<tr>
<td>Carer</td>
<td>A person who provides a substantial amount of care on a regular basis, who is not employed to do so by an agency or organisation. A carer is usually a friend or relative looking after someone who is frail or ill at home. <a href="http://www.carersonline.org.uk/">http://www.carersonline.org.uk/</a></td>
</tr>
<tr>
<td>Children’s trust</td>
<td>Children’s trusts are new organisations that are being piloted to plan, commission and finance children’s services. They will bring together education, health and social services under the control of local authorities, which will either run them directly or contract them out to public interest companies. These trusts will be modelled loosely on care trusts, which provide integrated health and social services for older people and/or those with learning disabilities or mental health problems. <a href="http://www.doh.gov.uk/childrenstrusts/">http://www.doh.gov.uk/childrenstrusts/</a></td>
</tr>
<tr>
<td>Community care</td>
<td>The provision of services and support to people to enable them to live independently in their own home or in homely surroundings in the community, including residential and nursing homes.</td>
</tr>
<tr>
<td>Community mental health team</td>
<td>Multidisciplinary teams made up of a mix of psychiatrists, social workers, community psychiatric nurses, psychologists and therapists. Provide assessment, treatment and care for individuals and groups with severe and enduring mental health problems, outside hospitals.</td>
</tr>
</tbody>
</table>
Connexions
All-encompassing youth service launched in April 2001 to replace the careers service and other statutory youth services in England. Aimed at giving 13 to 19-year-olds “the best transition to adulthood”. Involves personal advisors going into schools, colleges and communities to steer young people towards goals and guide them to relevant services. http://www.connexions.gov.uk/

Contracting out
The practice of purchasing services from charities and other organisations by local authorities and other statutory bodies.

CPN
Community Psychiatric Nurse

Day care
Daytime care is usually provided in a centre away from a service user’s home, covering a wide range of services from social and educational activities to training, therapy and personal care.

DDA
The Disability Discrimination Act 1995 introduced new measures aimed at ending the discrimination which many disabled people face. It protects disabled people in the areas of employment, access to goods, facilities and services, the management, buying or renting of land or property, and more recently, education. http://www.drc-gb.org/law/dda/asp

DfES
Department for Education and Skills http://www.dfes.gov.uk/index.htm

DH

Direct Payments
Money given to individuals to pay for care services on the basis of a community care needs assessment. http://www.doh.gov.uk/directpayments/index.htm
<p>| <strong>Disabilities</strong> | There are many different definitions of disability. The DDA defines a disabled person as someone with a ‘physical or mental impairment which has a substantial and long-term adverse effect on their ability to carry out normal day-to-day activities’, and includes different types of disability such as learning difficulties, mental health problems, chronic ill-health, autism spectrum disorders, and other types of disability. |
| <strong>Disability team</strong> | A team consisting of social work managers and occupational therapist care managers who work with people with physical disabilities and older people. |
| <strong>DRC</strong> | The Disability Rights Commission is an independent body set up by the Government to help secure civil rights for disabled people. Advises the Government as well as campaigning to encourage good practice, eliminate discrimination and promote equality. <a href="http://www.drc-gb.org/">http://www.drc-gb.org/</a> |
| <strong>DSA</strong> | Disabled Students’ Allowance <a href="http://www.dfes.gov.uk/studentsupport/students/stu_students_with_d.shtml">http://www.dfes.gov.uk/studentsupport/students/stu_students_with_d.shtml</a> |
| <strong>DWP</strong> | The Department for Work and Pensions (DWP) is responsible for the Government’s welfare reform agenda. Its aim is to promote opportunity and independence for all. It delivers support and advice through a network of services to people of working age, employers, pensioners, families and children and disabled people. <a href="http://www.dwp.gov.uk/">http://www.dwp.gov.uk/</a> |
| <strong>FE</strong> | Further Education |
| <strong>FEI</strong> | Further Education Institution (e.g. a tertiary college) |</p>
<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
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</thead>
<tbody>
<tr>
<td>HE</td>
<td>Higher Education</td>
</tr>
<tr>
<td>HEI</td>
<td>Higher Education Institution (e.g. a university)</td>
</tr>
<tr>
<td>Incapacity Benefit</td>
<td>A welfare benefit paid to people of working age who are unable to work due to disability or illness.</td>
</tr>
<tr>
<td>Joint funding</td>
<td>Where two or more agencies, for example, health and social services, agree to share the cost of running a project or service. <a href="http://www.doh.gov.uk/jointunit/partnership.htm">http://www.doh.gov.uk/jointunit/partnership.htm</a></td>
</tr>
<tr>
<td>Joint Investment Plans</td>
<td>Plans for purchasing care services jointly, produced by health authorities and local authorities as well as other key agencies and representatives of service users and carers.</td>
</tr>
<tr>
<td>LA</td>
<td>Local Authority</td>
</tr>
<tr>
<td>LEA</td>
<td>Local Education Authority. Council department responsible for delivering primary and secondary education.</td>
</tr>
<tr>
<td>Learning difficulty</td>
<td>A term covering people who experience more problems than the general population with activities that involve thinking and understanding.</td>
</tr>
<tr>
<td>Learning disability</td>
<td>According to Valuing People (Department of Health, 2001), learning disabilities can be defined as ‘the presence of impaired intelligence (a significantly reduced ability to understand new or complex information and to learn new skills) combined with impaired social functioning (a reduced ability to cope independently). These will have begun before adulthood and will have had a lasting effect on development.’ This definition encompasses people with a broad range of disabilities and does not normally include those who have a specific ‘learning difficulty’ in an educational sense, such as dyslexia.</td>
</tr>
<tr>
<td>Term</td>
<td>Definition</td>
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<tr>
<td>LSC</td>
<td>The Learning and Skills Council is responsible for funding and planning</td>
</tr>
<tr>
<td></td>
<td>education and training for over 16-year-olds in England. Established in</td>
</tr>
<tr>
<td></td>
<td>April 2001, the national LSC is a Government body that co-ordinates and</td>
</tr>
<tr>
<td></td>
<td>funds training and education initiatives to improve opportunities for</td>
</tr>
<tr>
<td></td>
<td>adults.</td>
</tr>
<tr>
<td>MLD</td>
<td>Moderate Learning Difficulty</td>
</tr>
<tr>
<td>New Deal</td>
<td>A number of schemes that aim to move the long-term unemployed into the</td>
</tr>
<tr>
<td>initiatives</td>
<td>job market through training, work placements and subsidised employment.</td>
</tr>
<tr>
<td>Nursing home</td>
<td>A residential home that has qualified nursing staff available to provide</td>
</tr>
<tr>
<td></td>
<td>nursing care.</td>
</tr>
<tr>
<td>Office of the Deputy Prime Minister</td>
<td>Formerly the Department for Transport, Local Government and the Regions. The department no longer handles transport, but is responsible for housing, regeneration and local government.</td>
</tr>
<tr>
<td>PA</td>
<td>Personal Advisor</td>
</tr>
<tr>
<td>PCT</td>
<td>Primary Care Trusts evolved from primary care groups, PCTs are free-standing statutory bodies that provide primary and community services and commission secondary (hospital) care on behalf of their local population.</td>
</tr>
<tr>
<td>Primary care</td>
<td>Services provided by family doctors, dentists, nurses, midwives, health</td>
</tr>
<tr>
<td></td>
<td>visitors, pharmacists, optometrists and ophthalmic medical practitioners.</td>
</tr>
<tr>
<td>Provider</td>
<td>Any body providing health or social care under contract arrangements with</td>
</tr>
<tr>
<td></td>
<td>a purchasing body.</td>
</tr>
<tr>
<td>Term</td>
<td>Definition</td>
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<tr>
<td>--------------------</td>
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</tr>
<tr>
<td>Referral</td>
<td>A request for help for someone in need of an assessment, usually written down in brief notes. These are usually made on behalf of someone else by a third party, for example a social worker for a service user, or a GP for a patient.</td>
</tr>
<tr>
<td>Residential home</td>
<td>A category of homes that provide personal care and other services and whose work has to be monitored by local authority registration and inspection units.</td>
</tr>
</tbody>
</table>
| Respite care       | Care provided by a day or residential centre or by a family as much for the benefit of the carers as for the person concerned.  
http://www.caringmatters.dial.pipex.com/defnresp.html |
| Ringfencing        | The Government’s practice of earmarking for national priorities parts of the funding it gives organisations such as councils and hospitals – effectively telling those organisations how to spend some of their money. At present, money is ringfenced for spending in areas such as mental health and education. |
| Scottish Executive (SE) | The Scottish Executive is the devolved government for Scotland. It is responsible for most of the issues of day-to-day concern to the people of Scotland, including health, education, justice, rural affairs, and transport.  
http://www.scotland.gov.uk/who/dept_education.asp |
| Self-assessment    | A means by which people set out their own estimation of their needs for support, usually on a standardised form. |
| SEN                | Special Educational Needs (additional needs)                                                                                                                                 |
| Sensory impairment | An absence or loss of the ability to hear or see, not necessarily a complete loss.  
http://www.sense.org.uk/sensory_impairment/intro.html |
<p>| Services           | Refers to a wide range of different services, support and equipment (see Section 1.5.3 for a fuller definition) |</p>
<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Service user</td>
<td>An individual who uses, requests, applies for, or benefits from health or local authority services. They may also be referred to as a client, patient or consumer.</td>
</tr>
<tr>
<td>SFC</td>
<td>The Scottish Funding Councils are the non-departmental public bodies of the Scottish Higher Education Funding Council (SHEFC) and the Scottish Further Education Funding Council (SFEFC). Together they are responsible for funding Scotland’s 66 higher education institutions and further education colleges. <a href="http://www.sfc.ac.uk/">http://www.sfc.ac.uk/</a></td>
</tr>
<tr>
<td>SLD</td>
<td>Severe Learning Difficulty</td>
</tr>
<tr>
<td>Social services departments</td>
<td>These are the local authority departments in England and Wales responsible for the provision of personal social services. Established under the Local Authority Social Services Act 1970, they combined the former children’s, health and welfare departments. The services they provide include social work, home care and community care.</td>
</tr>
<tr>
<td>Statutory authority</td>
<td>An organisation that is required by law to provide public services and receives central or local government funding, for example, health authorities and local authorities.</td>
</tr>
<tr>
<td>Statutory services</td>
<td>Refers to services provided by the local authority as a matter of course. Examples of statutory services include benefits, social services, hospital treatment on the NHS and schools.</td>
</tr>
<tr>
<td>Supported housing</td>
<td>Catch-all term for accommodation for vulnerable people with care needs. Examples include sheltered housing for older people, homeless hostels, and accommodation for people with learning difficulties and mental health problems.</td>
</tr>
</tbody>
</table>
### Supporting People

New regime for funding the running costs of housing for vulnerable people, such as rough sleepers, older people and those with special needs. The money will be paid direct by local authorities to housing associations and other supported housing agencies. It replaces the former system, under which supported housing was funded by combination of Housing Benefit and grant from the housing corporation.  
http://www.spkweb.org.uk/HowItWillWork/4.5FAQ.htm

### Transitions

Refers to a move from one situation to another (see Section 1.5.1 for a fuller definition)

### Two-tier local government

A system under which county and district councils work together to deliver the full range of local government services. The smaller district councils tackle issues such as housing and tourism, while their larger county council delivers in areas such as education and social services.

### Unitary council

A local authority that delivers the full range of local government services itself, rather than splitting them between county and district councils. Usually covers urban or other built-up areas.
Summary

Introduction

This report is based on a qualitative study carried out by the National Centre for Social Research and the Disability Alliance on behalf of the Department for Work and Pensions. The focus of the study was on exploring how and why structural transitions in disabled people’s lives can lead to discontinuity in the provision of equipment and services, and how this can be addressed. This issue was highlighted by the Disability Rights Task Force (DRTF). In its consideration of the barriers faced by disabled people in obtaining equipment and services, the DRTF identified that transitions in disabled people’s lives are a key point at which they encounter discontinuity in service provision, and that this should, therefore, be a focus for particular attention.¹

Through a programme of research with service users, service providers and policy officials the main aims of this study were to:

• explore the nature of transitions which impact negatively on equipment and service provision;

• explore how and why people’s needs may change at these points; and

• address how continuity of provision and joint working between different providers of services to disabled people may be impeded by current procedural practices, legislative and systemic constraints, and budgetary systems and boundaries.

The research was designed to be sequential in structure, with each stage building on those that preceded it, and was carried out through in-depth interviews and focus groups. The first stage sought to explore service users’ experiences and to identify issues that could be explored with service providers. The barriers and solutions identified by service providers in the second stage of the research were then

explored with policy officials in the final stage of the study. A qualitative method was employed in order to explore the full range of issues across a wide range of service areas and impairment types. The research was not intended to be evaluative of any particular service or programme.

The focus of the research was on structural, rather than personal, transitions; the main types of transition covered in the research were:

- into, within and out of different educational settings, including schools, higher and further education, and other training activities;
- from child to adult services;
- into, within and out of employment;
- from one local authority to another; and
- between different living situations, including hospital, home, and different types of accommodation.

**Difficulties faced by disabled people making a transition**

There were a range of difficulties experienced by disabled people when making a transition in their life, e.g. a move within or out of education or employment, or between homes. The potentially negative impacts for service users as a result of making a transition can be grouped into two main issues:

- not getting the service they need: this includes a new need not being met or losing an existing service; and
- delays in getting the service they need.

Examples from the research where there was a loss of service included a child moving to a new school who lost on-site provision of specialist therapy, and an adult moving home to a new local authority who had to give up equipment provided as an adaptation to their former home. Examples of delays in receipt of service included someone starting a new job, but not having the necessary IT equipment in place when required, and structural changes not being ready in time for the start of term, thus delaying the transition from nursery to infants school for a child.

Alongside these negative impacts was the additional effect of the disabled person finding the transition process stressful. This could be caused by a lack of awareness about what is available, uncertainty about their eligibility, and anxiety about the impact of making the transition on current and future service provision.

From the user point of view, the following factors were identified as making a difference to how smooth a transition was:
• approach of the service provider – capacity to refer, co-ordination of the process including of assessments, level of transition planning;

• resourcefulness of the service user;

• availability of appropriate service, flexibility and transferability of service; and

• availability of information about appropriate services.

Barriers that impede the delivery of services during transitions

Interviews with a wide variety of service providers enabled the research to identify a range of barriers across different service areas. These can be grouped together by: i) level at which the barrier originates – some barriers may originate at a central Government level, whilst others have a less clear origin in that they could be created at a local delivery level, central level, or both – and ii) the type of barrier, for example, whether it has an organisational/structural, budgetary or procedural basis.

Centrally-driven barriers

Centrally-driven barriers existed as a result of aspects of national legislation or policy (or the lack of it). Barriers arose as a result of:

• Organisational structures: some service delivery is organised in a way that, from the user point of view, a single service is provided by a number of different organisations, agencies or different sectors (for example, a housing adaptations service provided by teams operating out of two different local authority departments, housing and social services). Similarly, two related services may be delivered via different organisations (e.g. health agencies and social services). This leads to a potential problem of lack of understanding between organisations about their role and purpose, as well as a lack of information-sharing about users. In turn this can lead to delays for a user, confusion over the process of accessing a service, or even losing a service through poor co-ordination of provision. Similarly, the autonomy of local authorities to determine local service provision is likely to lead to discontinuity of provision for people moving between authorities.

• Procedures designed for central programmes or to ensure national standards can create barriers to smooth transitions. Building regulations, for example, can introduce delays into the process of getting housing adaptations. Funding procedures in general can take time, leading to delays for a user in receiving their service or equipment.

• Budgetary or funding arrangements: budget boundaries together with the regulations and eligibility criteria governing the delivery of centrally-organised services (such as the Disabled Facilities Grant) meant that some people were not able to get a service they felt they needed (or only able to do so if they made a financial contribution). Shortages of resource (for example qualified staff or suitable housing stock) were felt to hinder the ability to provide speedy and smooth transitions for service users.
Central and/or locally-driven barriers

A further range of barriers hindering smooth transitions were identified as originating at either the point of service delivery (in other words at the local government level), at the central Government level, or both.

Organisational structures

The key barriers identified in this area were:

- flexibility of staff roles and responsibilities: there was a debate around the extent to which the roles of professional staff (responsible for assessments and service delivery) should be designed to be based around specialist skills or more generalist skills. A specialist approach might give a more focused service, but perhaps involve a longer delay for the user if there are limited specialist staff; a more generalist approach might involve a quicker contact for the user, but perhaps be more simplistic in its view; and

- demarcation of service delivery according to team structures: the division of professional staff into different delivery teams (for example, ‘child’ teams, or ‘mental health’ teams) could result in the need for greater liaison between each team, and hence the risk of poor co-ordination for the user. On the other hand, it could mean a more co-ordinated approach for the user; this depended on how the team ‘boundary’ fitted with their particular needs.

Procedures or lack of procedures

The key barriers identified in this area were:

- difficulties for users and other providers in finding out about a service: where users or service providers were not aware of the relevant services or did not know how to go about applying for them, it created an obvious barrier to accessing the most suitable service;

- the effects of multiple assessments or duplication of assessments: where a service or similar service was delivered by two different organisations, or two teams, this could result in more than one assessment, meaning a likely delay and probable confusion for the user;

- missing information or missing professional staff at assessments: not getting an appropriate service following a transition could come about because the full information was not provided at an assessment. Insufficient sharing of information came about through lack of liaison between service providers, and lack of knowledge of each other’s roles;

- insufficient liaison between organisations (and between local authorities) to manage and co-ordinate changes in user needs: ongoing changes in user needs could result in lack of appropriate service response when there was not enough proactive contact and liaison between service providers; and

- lack of planning and preparation for predictable transitions, such as moves between schools.
Budgetary or funding arrangements

The key barriers identified in the area of budgetary arrangements were:

- existence and management of budget boundaries: having to fund related services from separate organisational budgets could lead to delays in provision of services or equipment;

- consequences of financial year planning: if an application for a service (for example adaptations to a home) came at a point when the annual budget was virtually accounted for, then this could cause a delay (or possible loss of service) while waiting for the new financial year;

- inconsistency in scope or application of budget criteria: there could be differences in the way that criteria to determine service provision were applied i) between local authorities and ii) between different staff administering the same budget. This could lead to variability of experience for service users, but also might lead to changes in receipt of service, for example, following a move across a local authority boundary;

- uncertainty of contract renewal for contracted services: the fear of non-renewal of contract could hinder long-term planning for contracted services and therefore lead to discontinuity in provision for users;

- requirement for prioritisation due to limited budgets: a user who ends up being lower priority would be likely to have to wait longer for a service, or perhaps not get the service they would have liked; and

- limited funds available for joint working: joint working arrangements were said to involve considerable time and resources, especially in getting them established.

What is being done to address barriers?

National initiatives

A range of national policies and initiatives are designed specifically to help facilitate transitions and overcome some of the barriers identified in this report. Examples of these include:

- Connexions: aims to assist in making smooth and effective transitions from childhood through to adult activities such as further/higher education and employment;

- Integrating Community Equipment Services initiative: aims to bring together key agencies in the delivery of equipment by pooling health and social services equipment stocks and budgets. Key aims are to modernise services and to increase the number of people benefiting from equipment. This will include facilitating transitions out of hospital;
• Access to Work: provides advice and practical support to enable a disabled person to make a transition into work, or to stay in work; and

• Office of the Deputy Prime Minister (ODPM)/Department of Health (DH) guidelines for delivering housing adaptations: intended to address the difficulties faced around making housing adaptations; it recommends the creation of unified teams comprising occupational therapists and housing officials.

Many of the initiatives identified in the report are relatively new, and some may be implemented in different ways at a local level. It is therefore too early to know how they will affect transitions made by disabled people.

Local initiatives

There were also numerous examples of work being done locally to address some of the barriers to smooth transitions including:

• designing joint procedures to reduce duplication of assessments by health and social services;

• creating multi-disciplinary teams involving social services and housing to improve co-ordination of services; and

• using budgets flexibly between health and social services to avoid delays in hospital discharge.

Issues to consider for policy development

The report suggests the following areas for policy development, which are common across all policy areas and sectors:

• **raise awareness of services** among service providers so they can make appropriate referrals, and also among service users so that they know what to apply for. Alongside this, increased user choice and control over the process is likely to result in more successful (or at least less frustrating) transitions. Increasing awareness could be done at a national and a local level;

• **increase ‘joint working’**: although procedures and structures appear to be beginning to reflect moves towards joint working, there is scope for improvement here. Working collaboratively, carrying out joint assessments, setting up joint procedures, or joint teams that can pool budgets – all these should help to smooth a transition process for a service user. However, joint working can entail a financial cost, and this needs to be considered when developing ideas;

• **‘key worker’**: allocating someone to manage and co-ordinate the process of transition (a ‘key worker’) can ease the process for the user and appears to help create a more positive outcome;
• **widen existing initiatives and policies**: there is scope among some programmes to widen their remit in order to assist more people with transitions, for example, broadening employment programmes to include help with routes to self-employment, or ensuring that disabled young people who do not have a Statement nonetheless receive the additional support they need during a transition; and

• **focus on evidence-based initiatives and policies**: a concern voiced among respondents was that the need to be seen to be innovative in new initiatives could mean that insufficient attention was given to existing good practice. There is greater scope for new initiatives to demonstrate how they are building on existing effective approaches.
1 Introduction

1.1 Introduction

The National Centre for Social Research and Disability Alliance were commissioned by the Department for Work and Pensions to conduct a study of the provision of services, support and equipment to disabled people through transition points in their lives. This introductory chapter sets out the background to the study, its aims, methodology and scope, and outlines the structure of the report.

1.2 Background

The Disability Rights Task Force (DRTF) published the wide-ranging report on civil rights for disabled people, From Exclusion to Inclusion, in 1999. The report highlighted the fact that many disabled people are in receipt of services and equipment from a wide range of different agencies and service providers, including local government, voluntary organisations and other authorities.

While the Task Force acknowledged that agencies often work in close partnership at a local level to provide co-ordinated services to disabled people, they also found that this was not always the case. With regard to the provision of equipment, a lack of responsiveness to the specific needs of individuals, coupled with legislative boundaries to provision and disputes over budgetary responsibilities, has led to sometimes fragmentary provision. This led the DRTF to recommend that barriers to joint working in the provision of services and support should be tackled, and that particular attention should be paid to points of transition. They cited examples of where disabled people have had to return equipment they still needed to a public sector provider simply because they moved from one educational establishment to another. This, it was noted, led to ‘serviceable equipment being placed in store, delays for the disabled person in continuing with their education and further costs

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for another provider in purchasing new equipment’. Rather than being led by the organisational structure of service provision, there is clearly an argument for prioritising service users’ requirements instead.

The Government responded to this, and the DRTF’s many other recommendations, in the Towards Inclusion report. They agreed that co-ordination and joint working between the various agencies involved in providing services and equipment is important ‘at all levels from central Government Departments through to local public sector agencies delivering services on the ground’. The multiple interfaces between health, social services, education and employment agencies, and between public and independent sector providers, make this a challenging but necessary goal.

In September 2000, a cross-Departmental group was established to consider further the issues of improving the co-ordination of service provision across health, social and other local authority services, employment and education. The initial stage of this project took the form of a major seminar of disabled people, which highlighted and discussed many of the practical barriers and constraints. The research reported here builds on, and takes forward, this earlier work.

### 1.3 Aims and coverage of the research

The focus of this study was on exploring why and how structural transitions in disabled people’s lives can lead to discontinuity in the provision of equipment and services, and how this can be addressed. Other research has addressed more broadly the general barriers that can impede disabled people’s full participation in society, and the obstacles that disabled people confront in trying to access services. This study focused specifically on the systemic issues that can lead to discontinuity in provision when people experience change in their circumstances.

Through a programme of research with service users, service providers and policy officials the study set out to:

- explore the nature of transitions which impact negatively on provision of services and support, including equipment;

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3 From Exclusion to Inclusion, p.195.


5 Towards Inclusion, p.63.

• explore how and why people’s needs may change at these points;
• address how joint working between different providers of services to disabled people may be impeded by current procedural practices, legislative and organisational constraints, and budgetary systems and boundaries;
• summarise the scope of recent and planned Government initiatives, and consider the impact these might have on the provision of services to disabled people; and
• identify where some of the gaps in initiatives persist.

This research did not seek to list the full range of possible barriers that disabled people face, nor did the research explicitly look at the quality of services (although this is inevitably tied in with users’ experiences of transition). Likewise, it was beyond the scope of the study to make regional comparisons, to provide a detailed examination of any particular sector of service provision, or to evaluate any individual programme or initiative. Rather, the emphasis has been on a cross-cutting exploration of how disabled people’s service provision is affected as their circumstances change, and what aspects of legislation, procedure or finance may impact on services at different stages in people’s lives.

1.4 Design and conduct of the research

The research was designed to be sequential in structure, with each stage building on those that preceded it. The first stage sought to explore service users’ experiences and to identify issues that could be explored with service providers. The barriers and solutions identified by service providers in the second stage of the research were then explored with policy makers in the final stage of the study. This design is reflected in the structure of the chapters in this report.

This study sought to explore the complex nature of service users’ and service providers’ experiences, to map the range of barriers that they faced, and to point to possible solutions to deal with these barriers. Because of its ability to identify underlying and unpredicted factors and causes, a qualitative research approach – based on depth interviews and focus groups – was used. It should be noted however, that qualitative research is not able to provide a measure of how prevalent particular behaviours or experiences are. The study is also not able or intended to provide an evaluation of any specific service.

The interviews and focus group discussions for each stage were conducted by interviewer specialists using a topic guide (provided in Appendix B) and usually lasted between an hour and an hour and a half. These were all tape recorded and transcribed verbatim.

The design and methodological conduct of the study are described briefly below, and in greater detail in Appendix A.
1.4.1 Selection of areas

The fieldwork for the first two stages of the research was conducted in six local authority areas in England, Scotland and Wales. These areas were selected to ensure diversity by the following criteria:

- region;
- level of deprivation according to the Index of Multiple Deprivation7 (England only);
- level of rurality;
- authority type (including London Unitary; District/County; Metropolitan; Welsh Unitary, and Scottish Unitary);
- social services star rating (2001, England only); and
- population size.

The authorities used in the study are not specified here, in order to preserve the confidentiality of the respondents that took part.

1.4.2 Stage one

The first stage of the research was made up of in-depth interviews with disabled service users who had recently experienced a transition in their life and focused on identifying the barriers that made transitions disruptive.

The aims of this stage of the research were to:

- explore the impact of transitions on service needs;
- examine the nature of any disruption to provision;
- determine factors that made for a smooth or a disruptive hand over of provision;
- focus on the impact of transitions on service provision, rather than on other general barriers or quality; and
- inform the stage two research with providers.

Stage one consisted of a total of 40 interviews carried out in the six local authority areas. The people interviewed were purposively selected to ensure that a range of characteristics were covered in terms of experience of transitions, disability type, services received, age and sex. Respondents were recruited to the sample through disability organisations local to the study areas.8

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8 Details of the recruitment process and the stage one sample profile are given in Appendix A.
Many of the disabled people in the sample had experienced more than one type of recent transition, had multiple disabilities, and at the time of the interview were in receipt of a variety of types of services, equipment and support.

### 1.4.3 Stage two

The second stage of the research was made up of in-depth interviews and focus group discussions with local service providers involved in the delivery of services to disabled people. The research took place in the same six local authority areas used for the first stage of study, but the interviews were not specifically about the individual service users who had been interviewed at stage one. Providers in statutory provision, and where relevant, providers in other sectors – such as local and national charities or private sector providers – to whom local authorities contract some aspects of support and service provision to disabled people, were eligible for inclusion in the sample.

The aims of interviews with service providers were to explore:

- the way in which the delivery of services, support and equipment is organised;
- the ways in which agencies or departments interface;
- areas of ease and difficulty this raises;
- steps taken to aid joint working; and
- perceptions of the factors that impact on continuity of service provision and joint working, especially legislative, budgetary, procedural and structural issues.

The focus groups were selected in order to bring together service providers working in related fields and/or with particular types of impairment. Drawing together people who work in different agencies and departments in the same area brought new insights into the challenges of joint working and the structural issues that impede it. Focus groups were used in addition to the in-depth interviews in order to explore interactively how these barriers between and across different sectors might be addressed.

The aims of the focus groups were to:

- explore further the barriers to service provision during transitions that emerged from the depth interviews; and
- generate strategic solutions to these problems.

Sixty-four service providers participated in the second stage of the research. These respondents were purposively selected to ensure that diversity in the sample was achieved in terms of service delivery areas. In the areas with a district/county council structure, service providers working in each were included. Recruitment for the in-depth interviews and focus groups involved initially approaching statutory bodies in each local authority area, and from these initial contacts mapping out to include contracted out services (especially in housing and transport). The interviews with
service providers made use of case study vignettes derived from the experiences of the service users interviewed in stage one.

Interviews took place at respondents’ place of work and a local, neutral venue was hired for each of the focus groups.

1.4.4 Stage three

The third and final stage of the research consisted of 20 in-depth interviews with policy officials working in central Government departments on disability-related policy.

The aims of the interviews with policy officials were to:

• identify recent, current and planned initiatives and ways of working to address the types of issues raised in stages one and two;

• understand the genesis of each and its particular objectives and focus;

• explore the extent to which, and the ways in which, they will address the issues identified in earlier stages; and to

• identify gaps, and explore solutions and barriers to those solutions.

1.5 Scope of the research

The research focused on the impact of transitions upon the delivery of services, but both ‘transitions’ and ‘services’ meant different things to different people. These understandings are described below. In addition, Section 1.5.2 describes the methods used by the research team to classify different types of barriers to smooth transitions.

1.5.1 Transitions

The focus of this study was ‘transitions’ – disabled service users’ experience of making a transition; service providers’ experience of enabling a smooth transition; and the contribution of policies and initiatives in facilitating or hindering transitions. A transition, for the purpose of this study, was understood to mean the move between one situation to another. The focus of the research was on structural, rather than personal transitions; the main types of transition covered in the research were:

• into, within and out of different educational settings, including schools, higher and further education, and other training activities;

• from child to adult services;

9 These included: Department for Work and Pensions; Department of Health; Department for Transport; Department for Education and Skills; Office of the Deputy Prime Minister, and the Scottish Executive.
into, within and out of employment;
from one local authority to another; and
between different living situations, including hospital, home, and different types of accommodation.

Various qualifications to this emerged during the fieldwork. The first was that while the focus of the study was on structural transitions, personal transitions can also impact on service needs and their delivery. Structural transitions generally involved a movement between organisations, locations, or types of economic activity. Personal transitions included changes to health and impairment, and changes within family composition and caring responsibilities, such as the breakdown of a relationship and children being born or taken into care, starting school, and leaving home. While the focus of this study remained largely on the impact of structural transitions on the provision of services, throughout this report references are also made to the impact of personal transitions, where relevant.

Other aspects of transitions include the fact that they do not necessarily occur at a single point, but may involve multiple steps or stages and may take place over an extended period of time. An example of this would be an individual making the transition from unemployment to employment. Their transition could be broken down into three stages. The first might involve preparing for work and requiring support from, for example, Work Preparation; the second the actual move into a job, which may require equipment being funded through Access to Work; and the third maintaining the job with ongoing support from another agency. Each of these could be seen as ‘mini’ transitions that make up the ‘unemployment to employment’ transition. Each transition can be viewed as comprising ‘making and maintaining’ a transition.

Transitions were also rarely experienced in isolation. Not only was a transition often made up of a number of stages or steps, but one type of transition often triggered, or was experienced alongside, others. For example, starting a course at a Higher Education Institution (HEI) could also mean moving across local authority boundaries, changing home, leaving employment, and enrolling with new local health care providers.

Broadly speaking, service users experienced the impact of a transition upon their services in one of three ways:

• no perceived change in provider and/or provision;
• a smooth and appropriate change in provider and/or provision; and
• a disruptive change in provider or loss of provision.

A ‘smooth transition of services’ was sometimes understood by respondents in the different stages of the study to mean different things. A transition that was smooth for a service user may have been achieved in a way that was very labour intensive and disruptive for the service provider, or vice versa, and with child transitions disruption and stress was often experienced primarily by the parent.
Service users were often unaware who provided their services. However, if they perceived no change where in fact there had been a change, that was considered to be a smooth transition. While achieving smooth transitions is a focus of this study, it should be noted that this in and of itself does not necessarily indicate the provision of good services. In fact, one aspect of service provision that emerged in the interviews with service users and which sometimes overshadowed the interviews' focus on transitions, was the generally low level and occasionally low quality of services being provided in the first place. Those not in receipt of services at all were not included in the sample. So, while we were able to get at the loss of particular services, we were only able to capture loss of all services as a result of a transition where the service user subsequently regained some level of service provision.

On the other hand, some service users were in receipt of multiple services, a smooth handover of some services could, therefore, be experienced alongside the loss or disruption of others, as a result of a single transition.

Impact of the different circumstances of a transition

Transitions occurred for a variety of reasons, and these are discussed in detail in each chapter. These reasons, however, can be broadly grouped into those that can be described as ‘chosen’ (for example the disabled person decided to make the transition) and those that were ‘forced’ (for example by the service provider’s lack of resources, the disabled person’s state of health or because of another aspect of their personal life). The concept of a ‘forced’ transition also related to changes that resulted from the structure of service delivery, for example the move between different age-defined tiers of schooling. A ‘forced’ transition, particularly in this respect, was not necessarily an ‘unwanted’ one but was usually one that could be planned for in advance. Indeed, within this type of ‘forced’ transition there was usually an element of choice. For example, although the system meant that at a certain age a child had to make a transition from, for example, an infant to a junior school, the parents and the child could exercise a degree of choice in terms of the type of school and the location of school.

A further difference in the circumstances of a transition, especially ‘forced’ transitions, is between those that were triggered by a ‘crisis’ (such as health, personal crisis, sudden closure of a provision) and those that were ‘plannable’ (such as moving between age-defined educational tiers, and transferring between child and adult services).

There did not appear to be a clear demarcation between the implications for service provision of a transition driven by the disabled person’s ‘choice’ or one that was ‘forced’ by the service provider or service delivery structure. There was evidence of service provider ‘forced’ transitions going smoothly because the existing service provider took a proactive role in ensuring a smooth transition to the new service provider. However, it did not always follow that a ‘forced’ transition, even one required by legislation, that was foreseeable and could be planned, was made smoothly. Similarly, transitions initiated by a disabled person could be very smooth
because the individual was in control of the process. Being able to exercise control and be proactive in relation to the transition process was important for the success of the transition from the user perspective; however, being able to exercise control was dependent on two things, having the opportunity to do so, and also having the capacity to do so.

Not making a transition
Transitions that did not happen were also relevant to this study. Some transitions were avoided either:

- because of a fear of the impact that they would have on services already received;
- because it was assumed that new service needs that would arise as a result of the transition would not be met; or
- due to a general ‘poverty of expectation’, whereby service users did not even consider the feasibility of some transitions as relevant to their own lives.

There are also situations where no move could be viewed as a transition. For example, an individual may need to move from their own home to more supported housing because their partner (who was their carer) has moved out. However, they may not want to leave their own home and make the transition to a different type of accommodation. Instead, they may be able to arrange a package of care that allows them to remain in their own home and avoid the move. But in terms of changes in service provision (new service requirements, increased service needs, possibly change of service provider, new assessments, possibly delays in receiving services) this individual may share the experiences of someone making a transition.

1.5.2 Classification of barriers
A core aim of the research was to explore the range of barriers underpinning a difficult transition for a user, and to provide greater understanding about these barriers and potential solutions. Throughout the report, we have sought to create clarity in understanding the different types of barriers by dividing them into different groups. We have used two types of grouping: the first identifies the nature of the barrier, this has been divided into three types:

- organisational – structural;
- organisational – procedural; and
- budgetary.

The second classification of barriers has been done in order to point to the location of the barrier in terms of either central Government legislation and policy, or local delivery: this distinction is introduced in Chapter 6. It was not always possible to pinpoint precisely whether a barrier identified by a respondent had a root in central or local policy or practice, and some barriers appeared to be the result of both central policy and local implementation. Centrally-driven barriers will generally require a
central ‘solution’, whereas barriers which have a local aspect to them could have either a central or a local ‘solution’, or both.

We have classified barriers with a central ‘root’ if they stem from: broader central Government policy direction (for example, the design of central Government programmes such as employment or education programmes; the structure of Government Departments having responsibility for the delivery of services that are related to each other (for example, housing and social services); and legislation or central policy guidelines around specific aspects of service delivery (the regulations for grants such as the Disabled Facilities Grant, Access to Work, or Data Protection, Health and Safety legislation, or Building Regulations).

Examples of barriers which we have classified as central and/or locally-driven are: co-ordination of services; resource shortages (staff, appropriate services or facilities, budget size); the structure of staff roles and functions within an organisation; lack of joint working around sharing of information and liaison both within and across local authorities; inconsistency in decisions about, or application of, eligibility criteria between local authorities; day-to-day organisation of a service (for example, hours of operation); and financial planning and prioritisation.

1.5.3 Services

Throughout the report the broad umbrella term ‘services’ is used to indicate a wide range of different types of services, equipment and support. In interviews, the interviewers took some time to probe the full range of types of services that service users might be receiving including:

- physical equipment for home and education/training establishment/workplace;
- adaptations to home and education/training establishment/workplace;
- transport and mobility services;
- advocacy/advice/personal support/buddy;
- residential, community and domiciliary care (including meals on wheels, personal care, shopping assistance);
- professional and health services (e.g. physiotherapist, occupational therapist, social worker, key worker);
- communication services (e.g. talking books, interpreters);
- allowances (e.g. Disabled Students’ Allowance); and
- vocational/employment support (including support in educational/training institutions).

Benefits were not covered under the remit of this study.
1.6 Reporting and interpretation

The primary aim of this research project was to explore the ways in which transitions impact on service provision, and what organisational and systemic barriers and facilitators there are to achieving a greater continuity of service provision. The sampling approach adopted, therefore, was designed to cover as wide a range of different types of sectors, programmes, and initiatives as possible in order to be able to identify cross-cutting and common themes. The first stage of the study allowed us to broadly map the range of transition types and to explore themes that recurred. However, within the sample, only a small number of respondents would have experienced some particular types of services, initiatives and programmes. This means that the nature of the reporting about particular programmes and services must necessarily be generalised rather than specific and we are unable to make comparisons between different regions. Likewise, amongst the service providers that took part in the second stage of the research, only a few would have worked under any particular job title or within any one programme.

The different stages of the research took place within a particular context that impacts on how the results can be interpreted, as discussed below.

As mentioned above, the stage one results should be understood with the following context in mind:

- general levels of services were low, sometimes of poor quality and service users often were not receiving services that they wanted to be. This sometimes made focusing on the specific impact of transitions on service provision difficult;
- transitions could be experienced by service users as highly stressful;
- a change in provision was not always a result of a transition; and
- service users were often not aware of what services they received and from whom.

The second stage of the research had to focus somewhat more broadly than on just transitions, so that joint working and general improvements to delivery could also be tackled. We were also reliant on service providers to build up a map of provision, but where they did little joint working then this perspective tended to be narrower. Some respondents, those with an ‘overview’ and who had worked in other teams and sectors, were generally better able to generate solutions.

Reporting on, and conclusions drawn from, the third stage of the research had to take account of issues of confidentiality around planned initiatives.

Where quotes have been used in this report they are attributed to a respondent described by various characteristics such as gender, disability type and age, as appropriate. All names, and where necessary some other characteristics, have been changed in order to preserve the confidentiality of respondents.
1.6.1 Structure of the report

The report is made up of five further chapters.

The next four chapters follow broadly the same format as each other. Each of these chapters first describes the nature of any discontinuity to service provision experienced by service users as a result of a transition. The chapters then explore the barriers and facilitators to achieving smooth transitions from the perspective of service providers and policy officials, outline the implications of recent national policy and initiatives, and provide a chapter overview summarising the key issues.

Chapter 2 focuses on children, in particular on child educational transitions and the transfer into adult services. Transitions into, within and out of further, higher and adult education are dealt with in Chapter 3, and employment transitions are dealt with in Chapter 4. Chapter 5 explores moving house, both within and across local authority boundaries, and how this impacts on services received at home. Finally, an integrated overview of the key barriers to, facilitators of, and areas for policy development for, smooth transitions is presented in Chapter 6.

Appendix A contains full details of the research methodology. The topic guides and example vignettes are reproduced in Appendix B.
Chapter summary

Disabled children and young people experience a range of transitions as they grow up, particularly as they enter and progress through the education system and move from child into adult services and activities. These transitions can be experienced by young people and their parents in such a way that a smooth continuity of service provision is maintained, but many encounter disruptions. The following factors were identified as helpful to smoothing transitions: coordination of services, communication and information (e.g. through a named service co-ordinator, ‘chaser’, or key worker); co-location of services and multi-disciplinary teams; support for parents and the involvement of parents and young people in transition planning that is clear, realistic and regularly reviewed and updated; and an appropriate type and level of on-site services at educational settings, provided in a flexible way.

Service providers were able to identify a number of factors that can make it difficult for them to ensure that transitions are experienced smoothly by service users. These included: lack of information for planning to meet an individual’s needs and to predict authority-wide needs; staff shortages, especially in the allied health professions; the lack of transparency and awareness of how different children’s services across education, health, housing and social service are structured; the lack of resources specifically allocated to supporting joint working ventures (such as increased pooled budgets, outreach or integration programmes or investment in cross-organisational computing systems).
2.1 Introduction

This chapter explores the impact of various educational transitions on the delivery of equipment, support and services to disabled children and young people. Educational transitions include a diverse range of changes, from moving into early learning provision through to the transfer out of compulsory education into further education, training, employment or other daytime activities. This latter transition has been the focus of considerable attention in recent years, in particular in terms of the parallel transfer from child to adult services, which is also explored in this chapter. The transition into adult activities will also be explored in the relevant chapters on adult education and training (Chapter 3) and employment (Chapter 4).

While this chapter focuses primarily on the experiences of children, young people and their parents, these respondents will also be included in other chapters, in particular in terms of issues around housing adaptations and changes in accommodation (Chapter 5).

The impact of moving across local authority boundaries and between long-term hospital stays and home on the provision of educational services, however, is included here. This chapter begins by describing the range and nature of the educational transitions experienced by young disabled service users in the sample, using case studies to illustrate their impact on service provision. The chapter then explores the organisational, procedural and budgetary issues that emerged in the interviews with service providers around ensuring a smooth transition. Finally, developments in policy and legislation discussed by service providers and policy officials are described.

2.2 User views and experiences

The first part of this section, drawing on the interviews carried out with young people and their parents, describes the nature and range of child transitions, the second part outlines the impact that such transitions can have on service delivery, and the third part of this section lists the factors that emerged as influencing why some transitions were experienced more smoothly than others.

2.2.1 Context of child transitions

A small number of children and young people were interviewed as part of the sample of disabled service users. These respondents, generally, had more severe and multiple disabilities and learning difficulties than the adult service users in the sample, and a considerably higher level of service use. The interviews were conducted with both the young person and one of their parents (usually also the
primary carer). This was considered appropriate given the study’s focus on the mechanisms of service provision and the key role that parents play in both providing and negotiating this.¹⁰

Transitions between different types of educational providers included moving between:

- different age-defined tiers of educational provision (e.g. between nursery, primary and secondary schools and colleges);
- different types of mainstream and special provision (e.g. between mainstream school, special unit within a mainstream school or college, and Moderate Learning Disability (MLD), Severe Learning Disability (SLD), hearing impaired or other disability-specific school); and
- no provision; hospital-based, home-based and respite-based learning; and educational institution-based learning.

These different types of transition were not necessarily separate, but rather tended to overlap so that, for example, the move from primary to secondary school was also a transition between mainstream and special provision.

Transitions occurred for a variety of reasons, some relating to a change of circumstances for the individual or their family, and some as a result of external factors. Individual reasons included:

- the child or young person’s age;
- illness, medical treatment, and regular or long-term hospital attendance;
- a change of residence across local authority boundaries; and
- the young person’s belief that he/she were unable to ‘cope’ with a mode of educational provision.

Schools had also expressed to disabled young people and their families that they perceived themselves to be unable to ‘cope’ with providing for the young person’s educational and other needs. External factors triggering a change in educational provider also included issues of capacity in local schools and education providers, availability of suitably accessible school buildings, and the Local Education Authority’s (LEA) preferences and professional advice regarding suitable provision in the local authority.

¹⁰ In the interviews with adult service users, generally only transitions experienced in the last year or two were considered. However, with children and young people, transitions across a longer time frame were considered. This was largely due to the importance of capturing the accumulative impact of multiple educational transitions on young people and their families.
Moving to a house in another local authority, or even to another house in the same local authority, had not been recently experienced by any of the families in the sample. Some families felt that they could not move because of the substantial investment and effort they had made adapting the property to be suitable to the needs of their disabled child. Another family wanted to move because ‘this home is just not safe’ for their son, but had remained on the waiting list for several years due to a lack of suitable social housing in the area. Effectively, the choice to move home was either avoided because of the feared impact on services (such as home adaptations and continuity of educational provision) or was prevented by the lack of alternative properties made available to families. This was compounded by the financial difficulties suffered by families with disabled children, which meant that they were often dependent on local authority housing providers.

When asked about possible future transitions, older young people and their parents expressed some hope about participating in supported employment in the future. However, all of the older young people and their parents spoke of their great anxiety about what the approaching transfer into adult services would mean.

‘We just want him [after transition to adult services] to go to a centre that’s like him going to school, you know, like we know that he is well looked after and well cared for at school so we don’t worry... if we can find a place like that for him when he’s older...’

Mother of 16 year old with severe learning difficulties and physical impairments

As the quote above illustrates, while recognising that the nature of provision after transition into adult services would have to change, a primary concern of disabled young people and their parents was that this transition should have as little impact as possible on the nature and amount of support that they received.

**2.2.2 Impacts of child educational transitions on service provision**

As described above, many transitions experienced by young people were ‘forced’ in some way by the system of service delivery. These transitions, for instance the age-triggered move between schools or into adult services, were generally predictable and so could have been planned for in advance. This section considers the impact that some of the transitions described above had on the continuity of services received by respondents and their families.

Educational transitions could have a major impact on service delivery as several types of services, such as physiotherapy, occupational therapy, and speech and language therapy, were often provided at the educational institution. This was particularly likely to happen on the site of special schools, often making the transition from a mainstream to a special needs provider ‘smoother’ in terms of ensuring continuity of service provision or an increase in service provision due to transition.

The movement between two education providers was sometimes felt to be very smooth, with parents perceiving no change in the delivery of services. However,
other young people experienced a variety of types of discontinuities, and these could be broadly grouped into the following:

- delay in getting a service;
- the loss or gain of a service;
- change in the co-ordination and accessibility of services;
- a new service need not being met or being newly met; and
- change of service provider or type of service received.

Delay in getting a service, support or piece of equipment

When a disabled young person was undergoing an educational transition, delays were experienced either a) in terms of disruption to non-education specific services as a result of the educational transition, or b) in terms of the transition itself not taking place when it was supposed to, resulting in a delay in the commencement of the new educational provision.

Disruptions to general services as a result of an educational transition included delays in getting IT equipment that was received at the previous school and delays in the transfer of disabled children’s medical and educational records between schools. The case study below outlines an example of the second type of delay, where there is a delay in the educational transition actually taking place.11

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Lucy is 5. She has Spina Bifida, several other chronic debilitating conditions, and learning difficulties. She cannot walk, needs assistance with going to the toilet, and can talk a little. Lucy was at a special nursery school prior to being allocated a place in a special unit attached to a mainstream primary school. The new school building had to be adapted so that there was space for her to be catheterised and for storage of equipment. Despite the head teacher informing ‘County Hall’ a year prior to the planned transition, the building work was left to the last minute. Lucy’s mother was unaware of the delay until near the proposed start of term and Lucy’s eventual start date was put back a term. Her mother had to call emergency meetings, ‘throw my weight around’, and be in regular contact with County Hall to get the building work done. Lucy’s start date was then put back further into the next term to allow for teachers to get training in lifting, handling and catheterising. Fortunately, the previous nursery was able to keep Lucy on, although this meant that they had to ‘bend the rules big time because by this time she was over five’. Since Lucy began at the new primary school she has been receiving physiotherapy and occupational therapy on site, which are services she did not receive when she attended the nursery.

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11 In this and the other case studies used in this report, names and some of the personal details have been altered to retain the anonymity of the individuals concerned.
This case study demonstrates the co-ordinator and advocacy role that parents often assume in order to ensure eventual service delivery, and the stress and anxiety that results from adopting such a role. The case study also presents the high value that parents place on effective communication and information exchange both between themselves and service providers and between different providers. In this particular case, the failure to plan which resulted in delays was felt by the parent to be the fault of the local ‘County Hall’ – which she had felt difficult to communicate with due to the lack of an identifiable person with responsibility for ensuring the work was done. Central building control regulations were also identified as contributing to the delay. Finally, the example above illustrates the benefit that resulted from the nursery school’s ability to respond to a crisis situation by being flexible and through being able to allocate spare capacity for dealing with emergencies.

**Loss or gain of a service, support or piece of equipment**

Child educational transitions sometimes resulted in the young person losing an existing service, support or piece of equipment, and sometimes in gaining a new one. These could both happen at the same time. Reasons for this discontinuity included variation between the two educational providers in terms of:

- on-site availability of services (e.g. on-site provision of specialist equipment and therapies);
- ethos and practices (e.g. whether the school’s approach is to ensure that ‘all pupils have to be treated exactly the same’ or to emphasise tailoring provision specifically to individual’s needs); and
- special needs focus (e.g. whether the school caters for all abilities, for pupils with a range of different special needs, or for pupils with a specific type of disability or level of learning difficulty, affecting the nature of the academic or physical activities and support provided).

The case study below illustrates how one respondent’s needs were not met by being in either a mainstream sixth form college, where academic pressures were too great, or in an SLD special college, where most of her fellow pupils could not read or write.

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**Susan** is 17. She has several chronic health conditions, mobility and sight impairments, and learning difficulties. Some years ago she went into hospital after becoming ill. She remained there for two years, partly due to delays in housing adaptations being completed. For her first year in hospital she received no teaching and only after her parents insisted was two hours a week provided. Susan attended a mainstream secondary school with a special unit. She worked well and achieved several GCSEs. She was keen to continue studying and the school said that she did not need to change schools but that adjustments would be made to the academic programme in the school’s sixth form so that she could continue there. However, no adaptations were made and the support... Continued
she had received before was withdrawn. She was the only pupil with special
needs to stay on at the school and she soon felt very isolated and depressed.
Both Susan and the school stated that they could not ‘cope’ and Susan
transferred to a special college focusing on basic life skills and physical exercise.
Through the transition Susan has lost academic stimulation. Because she cannot
cope with physical activities due to exhaustion, her week has been reduced
from five days to three days, and because of the emphasis on physical activities
she is no longer entitled to the physiotherapy she received before. The new
college does not have hydrotherapy on site, so this service has been lost too.
Susan and her family are now extremely anxious about what the implications
will be when she must transfer from child to adult services.

This case study demonstrates how each of the three factors given above can lead to
the loss or gain of services as a result of an educational transition. Susan experienced
the loss of specialist hydrotherapy treatment because of the lack of on-site provision
of equipment at the new educational provider. Because Susan’s new college had a
policy of treating all pupils in exactly the same way, Susan lost some of the individual
services she had been permitted at her previous school, such as the use of a room for
resting in during the day. Finally, the new college focused specifically on the needs of
pupils with severe learning difficulties; this resulted in Susan – whose learning
difficulties were less severe – losing out on educational provision that stimulated her
intellectual capabilities.

Service provision for young people and their parents also increased or decreased
with a change in health or in response to a parent’s experience of a personal
transition. Although an increase in services, particularly in support, at such times was
valued by parents, the sometimes sudden withdrawal of extra services could be
bewildering. One parent described how the additional support she had received
with caring for her disabled child after the death of her new baby was of great
benefit, but that she felt betrayed and confused when that support unexpectedly
stopped while she was still grieving. Likewise, parents felt that short-term fluctuations
in their child’s health led to services stopping and starting, leading to a lack of
continuity in service provision.

‘...gradually the carer began to come less and less and then she had given me
the notice that they’d decided, the panel decided that John was not sick
enough..., that they should stop the service. I was really angry with them
because I says to them in the beginning if you’re going to give me the service
please don’t stop it and if you’re going to stop it there’s no point you getting
involved in my life because my son’s going to take a downfall [if you go] and he
did take a downfall, he couldn’t understand why the service was stopped, I’d
explained to him it’s finished but he couldn’t understand why it finished.’

Mother of 8 year old boy with severe learning, sensory and physical
impairments
The transition from child to adult services was also associated with the loss of provision. One example of this was a disabled service user with cerebral palsy who lost the regular physiotherapy sessions that she had received as a child once she became 19. The reason she was given for this was that as an adult she was no longer entitled to receive this service. Service providers also cited the loss of language therapy that occurred when young people left compulsory schooling.

Change in the co-ordination and accessibility of services

Rather than lead to the gain or loss of services, child transitions between education providers sometimes resulted in a change in how well co-ordinated and accessible services were. Some disabled children and their parents found that moving from a mainstream to a special educational provider resulted in an improvement in the availability of some services on site and made it easier for them to access, and therefore utilise, particular services. This also served to improve communication between the service providers, young people and their parents. One example of this was a school which one respondent attended that had occupational and other therapists based on site. Pupils had notebooks that they took to school and brought home each day, facilitating regular communication and exchange of information between the parent and therapists. Where therapists were not regularly accessible at the same school, this mode of communication would have been difficult to achieve.

A new service need not being met, or being newly met

Changes in educational provider were sometimes accompanied by a change in the service needs of the disabled young person. One example of a change in educational institution leading to a new equipment need was a young person who had to wait some months for a new wheelchair after her fitting, only to find that the primary school she had moved to since the fitting required finger guards for the wheels – these took several months further to arrive. Transport was often a new service need that was triggered by a disabled child’s transition to a new education provider, in particular if that provider was further away than the previous one or was in another local authority.

John is 8. He has severe multiple disabilities and chronic health conditions.

When John was ready to leave nursery his parents did extensive research and decided on a school outside of the local authority. The Education Department of their resident local authority put pressure on them to choose a local school, but the parents felt that none of these could meet John’s complex needs and fought for their preferred school. Attending a school in a different local authority meant that the family was now dependent on provision of transport services. John’s statement decreed that the driver and escort had to be medically trained because he was dependent on complex and varied medical equipment. John’s mother realised that the driver and escort had had insufficient medical training, and, despite repeated requests, nothing happened.

Continued
‘And then I had to go for my solicitor and my solicitor then got the social worker involved, she got the education involved, she got transport involved and I think soon after my solicitor got involved and gave them so many days to do something before we take them to court, we finally got a driver and an escort that’s fantastic … and they’ve been trained by a local nurse and they’re just fantastic….’

The development and emergence of changes in a young person’s disability can also lead to new service needs being identified. For example, as the full extent of one child’s acute hearing impairment was established, it became clear that a school able to teach him skills in communication would be important. This exposed the fact that education provision for hearing impaired children with multiple other impairments was lacking in the local authority, and that the local authority was reluctant for him to attend a school outside of its boundaries in order to meet this new service need.

Change of service provider or type of service received

Services and equipment supplied to disabled children and their parents was often supplied by voluntary agencies such as Barnardo’s. This, generally, both made them less affected by transitions between educational providers and, where the voluntary agency focused specifically on the needs of children, more affected by service users’ transfer into adulthood than they may otherwise have been.

Disabled young people and their parents perceived the transition between child and adult services as a sudden change of all service providers and types of services received. This was felt to be a very worrying transition point, both by those who had largely experienced continuity of service provision through transitions experienced as a child, and by those who had had a negative experience of the provision of children’s services and who had experienced disruptions in the continuity of service provision. The two quotes below illustrate this:

‘When he is an adult that’s what was worrying me because then the services change as well. Nothing changed when he changed school because the respite he was getting he got that the same as before. And they have physio and a speech therapist at school so, yes, so that still continues. But in the day centres that’s different…, its not like an education centre.’

Mother of 16 year old boy with a history of smooth provision of child services
Susan’s mum: ‘She’s saying she’s worried about next year, she has to go to adult services and the transition of that, and if you’ve got all these problems when they’re a child, what you’re gonna...’

Interviewer: ‘What is it that worries you, Susan, about moving into adult services?’

Susan: ‘I’m the loser I think aren’t I?’

Susan’s mum: ‘She’s been told that she’ll lose her session worker... because when she’s nineteen she’s not entitled to it anymore... Once she goes to social services for adults it’s a completely different office... so your services will go along the same line as somebody who is fifty or sixty, you know you’re not treated like an adolescent.’

Mother of 17 year old girl with history of disruptive provision of child services

2.2.3 Factors influencing smoothness of child transitions

Various factors emerged from the interviews with disabled young people and their parents as impacting on the smoothness of transitions through the education system and into adult services. These can be broadly grouped into the following categories:

- co-ordination of services, communication and information;
- resourcefulness and involvement of parents;
- availability of appropriate services and approach of the school; and
- stability of transition planning and the statement of special educational needs.

Each of these factors is explored in greater detail below.

Co-ordination of services, communication and information

The parents of disabled young people felt that having a named co-ordinator of services or key worker would be one of the key factors that would ease transitions and anxiety about transitions, especially given the multiple contacts and assessments disabled children experience. Such a co-ordinator would be able to be a single source of clear and definitive information, someone from whom parents and disabled young people could obtain knowledge of what their entitlements and options are, and somebody who could effectively engineer and enable effective inter-agency working and communication:

‘What you could actually do with is one person overseeing Lucy’s care so, basically, I mean because I do that job at the moment and it can get really complicated and you could actually do with a co-ordinator who knows who Lucy goes to see because there are probably, oh, I’ve got a list of sort of 40 names of different people she sees and its co-ordinating it all and nobody else knows what anybody else is doing.’

Mother of 5 year old girl with chronic ill-health and learning difficulties
Some parents reported having had a named social worker in the past, but that this service had been stopped due to budgetary restraints, and now they did not know who in social services to contact for information and advice. But it was for parents of children who required a large amount of varied contact with health services for whom the co-ordinator role resonated most strongly. This was because those young people with complex health needs often had to see a very large number of different health professionals who did not liaise with each other in order to minimise the number of separate visits that disabled young people had to make to hospital.

The quality and capacity of individual service providers was felt to be a key factor: this included whether they turned up to reviews, whether they kept parents and young people informed, and how proactive and generally friendly they were. A General Practitioner or a regular transport driver was able to establish a relationship and provide some continuity across the transfer between two different educational institutions. Provision of services on site or at a co-located venue meant a greater likelihood that health professionals would be able to attend reviews.

The previous educational provider should be a major source of information about other schools to which pupils could potentially progress on to.

**Resourcefulness and involvement of parents**

The amount of information about, and familiarity with, ‘the system’ that a parent had emerged as important to how smoothly their child experienced a transition, but this did not mean that the transition was smoothly experienced by the parent. In fact, the achievement of a smooth child transition sometimes depended on high levels of parental involvement, anxiety and effort. The level of agreement between parents, the LEA and educational providers about what constituted the most appropriate type and level of service provision and entitlement was a major factor in determining smoothness of the transition.

As well as being the primary negotiator of services for their child, parents were also the primary carer. The parents interviewed had given up paid work to become full-time carers for their disabled child. Personal transitions in the lives of parents, therefore, also had an impact on the continuity of services provided to young disabled people. In addition to the strain of being a full-time carer, personal transitions that had been experienced by the parents in the sample included the loss of a baby, the loss of a partner and periods of acute financial crisis.

**Availability of appropriate services and approach of the school**

The availability of appropriate and accessible education providers was another factor impacting on the smoothness of a transition. Having to attend a school or hospital outside of the local authority area caused some problems to continuity of service provision both in terms of a change in transport needs and in terms of negotiations with the LEAs. Where there was a school in the local authority area which was not already physically accessible, this caused delays due to building
planning and works having to take place in an ad hoc and reactive way, rather than need being anticipated and accessibility being made prior to the individual need arising. Alternatively, if the child went to another school which was more accessible, this could result in their separation from their peer cohort.

Transition into a particular type of educational institution was sometimes determined by availability and the inclusiveness philosophy of the local authority. Some local authorities were perceived by respondents to emphasise the provision of special schools and units, while others were felt to place more emphasis on inclusiveness in mainstream schools. This difference determined not only what school places were available in the area, but also what advice and preferences educational providers expressed to families about the nature of educational provision their child should move into.

**Transition planning and the Statement of Special Educational Needs (SEN)**

Some of the schools attended by the young people in the sample had formalised and focused seriously on their process of planning for pupils’ transitions into the next educational or care provider or into adult activities and services. The existence of a clearly worded, well-explained and realistic statement that the young person could take with them across a transition was reassuring for both young people and their parents. Parents and young people also felt that continuity of service provision across transitions was assisted best where such transition plans were regularly updated and reviewed, as this kept them current and relevant. In those schools where the transition plans were not regularly reviewed, parents felt that the transition plan was dismissed by service providers as ‘paper work’. In a similar way, parents felt empowered by having an ‘official’ statement of their child’s special educational needs, as this was felt to form both recognition of specified level of service need and a legal document of entitlement. One parent in Scotland expressed concern about the proposal there to drop the Record of Need.

Parents also expressed anxiety about services that were being offered for a short period of time or that were ‘under review’. Uncertainty about the reliability or continuation of a service made it difficult for parents to anticipate and plan for the loss of the service.

### 2.2.4 Transport issues

‘I think in the early years transport was one of the biggest issues we had.’

Mother of 8-year-old boy with severe learning, sensory and physical impairments

Transport is a major issue due to the unsuitability of current public transport provision for many young people with severe disabilities, the fact that special schools are spread further apart, and the reluctance of some LEAs to provide transport services to a school in another local authority. Parents and young people expressed uncertainty about how local authority boundaries impacted on entitlement to
appropriate transport services. This results partly from a lack of signposting to appropriate sources of information and partly from a lack of consistency in the information received from different service providers (e.g. schools and transport providers providing contradictory information on entitlement). As seen in an earlier case study, one parent had to consult a solicitor in order to establish what their entitlement to transport provision was, and to force the local authority to comply in providing it.

Many parents felt pleased with the transport service their child received to school. It was the one area of service provision where parents had an opportunity to have regular face-to-face contact with the provider of a service to their child. For this reason it was particularly valued when the same individual transport provider came for a sustained period of time, as not only did this allow the young person to forge a relationship, but also for the parent to experience continuity. When one young person started at a new school, not only did the same taxi firm continue to take her to school, but also usually the same taxi driver as before as well.

When the transport unexpectedly changed, this caused great anxiety for parents. For example, parents wondered whether the new providers were fully briefed on their child’s needs, whether they had the required specific medical training or understanding of behavioural difficulties, and whether they had been police checked. Sometimes transport provision changed and the reasons why were not communicated to the parent.

There was anxiety about what impact the transfer from child to adult services would have on the provision of transport services. For example, one 17-year-old had started at a special needs unit which she could stay at until she was 25, but the family did not know whether she would still be entitled to transport provision to take her there.

2.3 Service providers’ and policy officials’ views about enabling smooth transitions

Interviews were conducted with professionals from a range of different service sectors to explore what they identified as the barriers to providing continuity of service provision when a disabled child or young person made a transition, and what might facilitate smoother transitions. The service providers cited in this chapter worked in both special and mainstream education provision, as well as in local authority social services, health and education departments. The policy officials referred to here include those working in the Department for Education and Skills, the Department for Work and Pensions, the Department of Health and the Scottish Executive. Service provider and policy official views about difficulties are reported.

Details of the sample of service providers and policy officials interviewed are provided in the methodological description in Appendix A.
under two headings below: structural and procedural barriers (Section 2.3.1) and funding and budgetary barriers (Section 2.3.2). In the section that follows these two, we look at recent developments in national policy and initiatives and at general facilitators and solutions proposed to address the barriers listed below.  

### 2.3.1 Structural and procedural barriers and facilitators

A range of different barriers around organisational structures and procedures were identified by service providers as impacting on continuity of service provision. These barriers are described under the following sections:

- structural barriers to joint working;
- lack of information and planning in the transfer to adults’ services;
- lack of communication and involvement of young people and parents in the transition process; and
- procedural barriers to joint working.

In some cases, service providers were either already employing solutions or were able to propose potential solutions to these barriers. These are described in more detail in Section 2.4.

#### Structural barriers to joint working

Service providers identified a range of persistent difficulties with joint working that made planning for and managing smooth transitions problematic, and contributed to a subsequent lack of co-ordination in service delivery. Service users had described how the lack of joint working between service providers contributed to the anxiety and confusion they felt at transition, and was a factor in the delays they experienced at such points. Structural barriers to joint working are described below, grouped under the following headings:

- variation in the structure of child services delivery; and
- variation in the structure of local authorities.

There was variation in how the delivery of services to disabled children was structured and where in the local authority it was located. Although regional variation was not considered to necessarily be a problem, it was felt that the range of structures was confusing for other service providers both within and outside of the local authority, and for parents and children trying to access services. Service providers described a range of existing structures, including the positioning of services for disabled children within the adult disability team, within the child services team, within a dedicated child disabilities team, as well as within a disability-

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13 A Department of Health produced paper overviewing the legal framework for the provision of equipment to disabled children is available on http://www.icesdoh.org/article.asp?Topic=96.
specific child team. There was no clear consensus as to which of these structures was preferred; however, there was agreement that Child Development Centres,\textsuperscript{14} with clinics at which health, social services and sometimes also education providers were present, were helpful in improving multi-disciplinary working and accessibility for users. The current work of the Child Development Centres and Children’s Trusts (which are also building on this multidisciplinary approach) are described in Section 2.4.

Delays also resulted from \textit{the structure of the local authority as a whole}. Some service providers felt that the division of responsibilities between district and county councils was confusing and contributed to delays. One local authority in the study had been divided into a city council and a county council, leading to a number of disabled pupils living close to the council boundary becoming ‘out of county placements’ and effectively undergoing a transition between local authorities. Placing a young person in a school outside of the local authority or council was felt by service providers to contribute to the home authority losing ‘overview’ and potentially leading to a lack of service co-ordination as a result.

Where service providers had worked in just one local authority, or even within a single department or team, it was felt that they might lack awareness of different models of practice and of other sectors’ time-scales and information needs. Job swaps, local and national directories and other solutions to this barrier proposed by service providers and policy officials are described in Section 2.4. Service providers also felt that while the sharing of good practice through newsletters, web sites and other mediums was helpful to some degree, that these should be selective and appropriate to ensure service providers were not deluged with information.

\textbf{Lack of information and planning in the transfer to adult services}

Both service users and service providers identified the transfer from child to adult services as highly problematic in terms of maintaining continuity of provision. One service provider, working in a social services adult disability team, described how recently “loads of eighteen year olds popped up out of nowhere”. The lack of prior information received by her team about these young disabled service users meant that no planning or preparation had been done and the resultant moves into adult services were responded to as ‘crisis’ transitions.

In response to the lack of reliable data for use in supporting the transfer to adult services, service providers and policy officials highlighted three areas where work had been done but where more was required:

- the need for collection of data for measuring authority-wide current and anticipated service need;

\textsuperscript{14} Refer to the glossary for a description of Child Development Centres and other terms used in the report.
• the lack of new teams and staff roles with the specific remit of co-ordinating transition into adult services; and

• required development of individual level transition planning.

Policy officials described how the new requirement currently being unrolled for **data collection about the nature and extent of SEN at the school and LEA level**, should yield data that will support both the planning of services at a national and regional level, and assist in identifying individual needs. Some service providers also felt that LEAs needed to have better information about their special schools and the client groups they serve in order to inform a clearer strategy for their future direction. Likewise, young people and their parents felt that they knew little about what impact moving into adult services would have on their service provision, and wanted to have the opportunity to be able to plan further in advance.

Frameworks for the **improved dissemination of good practice** were also cited by respondents as required. One policy official outlined a successful local initiative which was conducted with central Government funding. A region identified as having developed excellent Transition Planning procedures, set up a multi-partner working group with the specific remit of developing a CD Rom of resources for good practice that could be disseminated to other areas. This was an approach also designed to address the fact that information tends to flow from central development to regional providers, but with few mechanisms for the flow of information and specific good practices the other way.

**Lack of communication and involvement of young people and parents**

The parents of disabled children often felt that they were not sufficiently consulted or informed about changes in their child’s service provision. Service providers across different sectors also keenly felt that parents needed better information about service provision processes and that liaison was often marred where parents felt that their expectations about service delivery had not been met by providers or by the Statement of Special Educational Needs. The development of updated and comprehensive websites and directories was suggested. **Parent partnership and liaison** was also widely recognised as key to improving how smoothly transitions were experienced, in particular by parents themselves. Service providers felt that parents of the youngest children sometimes had a Child Development Centre in their area to assist with the co-ordination of services, and older young people

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16 The TransPlan CD ROM for the North East SEN Regional Partnership, the Government Office for the North East and Connexions, is available from the DfES Publications Centre.
sometimes had the support of a personal advisor, but children between these ages did not have a link person working with their families.

Local authority structures were experienced as complex and non-transparent by users and other service providers, leading to delays being caused by the wrong providers being initially approached. For example, service providers located in special schools said that they often received enrolment requests direct from parents who found approaching the LEA confusing or daunting. One solution suggested was that all local authorities should produce and circulate to parents and young people clear organisation charts with listings of responsibilities. Service providers working in schools recognised that the school needed to also function as a parent resource and meeting centre. The involvement of Parent Partnership Services and new parent liaison services were felt to be positive developments. These are discussed further in Section 2.4.

**Procedural barriers**

Service users and service providers recognised that there were various procedural barriers to achieving a smooth transition. These contributed to confusion over responsibilities and a lack of coherency in roles and communication. These are grouped into issues around bureaucracy and issues around schools’ admissions procedures.

**Bureaucracy** was identified by some service providers as an impediment to effective joint working between agencies or departments. For example, one head teacher of a special primary school wanted informal advice about a potential child protection case, but found that in one local authority she could not get advice without completing a long and formal referral form. In the local authority she had worked in previously, informal close working had been practised.

Young people and parents said that a key stage in the transition between schools, was getting accepted in the school felt to be most appropriate to the child’s needs. Some service providers, however, felt that **school admission procedures were not always functioning in the way they were designed to.** In some local authorities, admissions meetings were held very rarely; were poorly attended by Special Educational Needs Co-ordinators (SENCOs) or others familiar with the individual children’s needs; and documents were not summarised or read prior to the meeting. In one area, all the schools were gone through alphabetically at the meeting; there were two special primary schools in the area which meant that pupils from the primary school earlier in the alphabet tended to get most of the placements at the special secondary school in the area, with few places left for pupils leaving the other special primary school.

In other local authorities, admissions meetings were more regular, smaller, more focused, and attended by the SENCOs for each school in the authority. It was felt to be useful to have ‘thumbnail sketches’ of each child being discussed and an accurate and short summary of these prepared, and circulated so that they could be read prior
to attending. In some areas, close working had been developed between nursery, primary and secondary schools, with transition meetings held directly between the involved schools.\(^{17}\) This closer working was felt to have come about because of the highly motivated and co-operative head teachers at these schools. Transitions were smoother where school admissions could be dealt with throughout the year, and education provision maintained through the summer. The provision of some form of schooling during the summer was felt to be especially useful in supporting the transition between primary and secondary school, as otherwise the preparation undertaken prior to the summer break was lost. This was only rarely available, however. Variation between schools in terms of their holiday times also caused problems for phased transition between schools.

### 2.3.2 Funding and budgetary barriers and facilitators

Different aspects of the structure and level of funding arose in the interviews as affecting the continuity of service provision. These issues are described below, grouped into the following categories:

- resource shortages;
- contracted out services;
- budget boundaries; and
- variations in funding.

Although we did not set out in the research to focus on issues around resource shortages, it was a recurring theme among respondents, and was often at the root of the problems they identified. We have, therefore, reported it (in this and other chapters) before reporting other budgetary issues, in order to set a context for the remainder of the discussion, while acknowledging that it is clearly not the only barrier to provision of continuity of service.

Problems of resource shortages were felt to impact on transitions in a number of ways: leading to delays, an uncoordinated process, and possibly a loss of service. Parents of disabled children felt that the lack of co-ordination and communication between service providers meant that they had to take on the co-ordinator role themselves. Amongst service providers there was a general awareness and recognition of the need for improved models of partnership working to overcome this problem through such mechanisms as pooled budgets, joint aims, and shared equipment stores. However, some service providers felt that such partnership working was frustrated by there being only sufficient funds and time to meet prioritised basic statutory obligations. **Overall resourcing** was considered to be insufficient to support additional joint working practices, for example preventing investment in

\(^{17}\) Schools are under a statutory duty to pass on information when pupils transfer to another school and the revised SEN Code of Practice (effective from 2002) emphasises the importance of sharing information.
cross-organisational computing systems, increased pooled budgets, or properly resourced mainstream outreach or integration programmes. While general under-resourcing was recognised by both service users and service providers as a barrier to smooth transitions, the perception of relatively greater under-investment in adult services was also identified as a major factor adversely affecting the transition from child to adult services. Awareness of this contributed to young people's and their parents' anxiety about the transfer into adult services. Planning investment could also be difficult, for example, sometimes the requirements of one new pupil's statement were much greater than anticipated and, therefore, hard to plan for in annual budgeting. As in other sectors, service providers reported that the point in the financial year had an impact on whether or not certain equipment might be delayed, or be approved at all. Nursery schools, however, were often able to obtain specific equipment before parents, and thus equipment-sharing collaboration between institutions and parents was sometimes set up for portable supplies.

The fact that transport services tended to be.Contracts out, rather than provided in-house by the education department, contributed to some assessment problems arising and therefore meant delays or the inappropriate provision of a service. An example of this included initial assessments of disabled children's needs being undertaken by social services, but not gathering the information required by the transport providers (such as the size and make of a wheelchair, and the width and accessibility of the street). This raised the need for services that are contracted out, and therefore operating under a separate budget, to be fully integrated with partner providers in terms of joint working and communication. Having to reapply, sometimes even annually, for contract renewal made the planning of smooth provision of transport services problematic for contractees. One provider, who ran a bus service taking children with disabilities to school, stated that he delayed replacing a broken down minibus for some months until he knew his contract was to be renewed. This meant young people experienced delays in the service while he operated with a reduced fleet.

Some service providers found the negotiation of budgetary boundaries and responsibilities took a considerable amount of time to co-ordinate, re-deploying their time from other duties and contributing to the delays in service delivery that service users experienced. An example of this was the time-consuming re-negotiation of cost sharing a nursery school head teacher had to broker with health services for the school's nurse. This process was made more complex due to the local health services undergoing regular reorganisation of their management structure and changes of staff. The lengthy process of grant applications for funding through bodies such as the Lottery Fund, and the paperwork required after the grant had been used, was also cited by school staff as time consuming. Those schools that had an alternative source of funding that could be drawn on, such as a charitable trust, found this very useful in enabling them to adequately respond to crisis situations and to provide additional services such as playgroups through the summer to ensure continuity of service provision throughout the year. Disrupted service provision during the summer months was a problem also identified by the parents of disabled children.
Variation in the allocation and management of budgets at the LEA level led to some areas being better placed to provide continuity of services to children and young people than others. One example of this variation was an LEA that permitted the release of funds for special nursery school places and services prior to being statemented, while another neighbouring LEA would not permit funding such services until entitlement to a statement had been agreed, causing delays. Other flexible budgetary facilitators cited by service providers included the ability to fund private school places where this was required to quickly meet the needs of a disabled child or young person.

2.4 Recent developments in national policy and initiatives

The last few years have witnessed the introduction of a wide range of legislation and new policy initiatives aimed at the needs of disabled children, young people and their carers.\(^{18}\) The amendment made to the Disability Discrimination Act 1995 by the Special Educational Needs and Disability Act (SENDA) 2001, for example, means that LEAs and schools have a duty to develop, publish and implement strategies to increase access to school for disabled pupils. The duty, which became effective from September 2002, covers access to the curriculum as well as physical access to premises and facilities, and access to information in different formats.

This section draws on both the service provider and policy official interviews to look at aspects of national policy and local and national initiatives that have aimed to facilitate smoother child transitions.

Despite the establishment of various working groups to tackle aspects of transitions as experienced by disabled children and young people, the interviews with policy officials did show how the provision of services to disabled children was divided primarily between the Department for Education and Skills and across the Department of Health, and therefore, that it was vulnerable to absences of cross-departmental working. Recent structural changes in central Government may go some way towards integrating the various responsibilities. The role of Minister of State for Children has been created, alongside the integration of children’s policy in the Department for Education and Skills. This should provide a single departmental focus for disabled children, hopefully contributing to improved co-ordination within children’s services (including family and parenting support), and between these services and mainstream schools and education policy.

DH and DfES are planning to publish a Children’s National Service Framework (NSF) in 2004. The NSF will set national standards for health, social care and education to be obtained jointly. The new standards aim to ensure better access and

smoother progression in the provision of services for children, from initial contact with the NHS via a GP surgery or NHS hospital, through to social services and education support. One of the key areas being addressed by the NSF is transition services into adulthood for disabled young people.

DfES is planning to publish the new SEN Action Programme early in 2004. The programme aims to build on current activities and address issues highlighted in the Audit Commission’s 2002 report Special Educational Needs: a mainstream issue. It will combine both short-term and long-term goals, spanning the next 10 years. No future changes to the statutory framework for SEN are proposed in the Plan, but it will concentrate on providing practical support for teachers and schools, LEAs and other providers. It covers access and inclusion issues such as developing roles for special schools to work in partnership with mainstream schools and addressing the problems encountered by some parents in gaining admission for their children to local schools. Supporting transitions is a focus of the Action Plan and it is designed to link into the national strategy for 14-19 education and training. The programme will be directly relevant to improving transitions and its aims include:

‘Improving the outcomes for young people with SEN and disabilities as they make the transition between phases of education and from education to work and adult life through better multi-agency planning and co-ordination of advice and services. The Connexions service has a vital role to play.’

In the interviews with service providers and policy officials, the scope of recent and planned policy developments and their likely impact on the ability to deliver smooth transitions was discussed. Some of these recent developments are described below, in terms of how they will seek to address the following barriers:

• **lack of service co-ordination and parent liaison** (through Child Development Centres and Children’s Trust pilots; SEN Regional Partnerships; Transition Champions within Learning Disability Partnerships; Parent Partnership Schemes, job swaps and local and national directories);

• **lack of information and planning for transitions** (through inclusion of SEN in the Pupil Level Annual Schools Census and the Valuing People strategy);

• **loss of services as a result of transition** (through tackling the shortage of speech and language therapists and other provision);

• **failure to identify service needs** (through improved identification of hearing impairment in children); and

• **service discontinuity and loss at transition into adult services** (through the Connexions strategy; Inclusiveness Projects; transition teams; transition planning; the BRITE Initiative and Centre; and changes to Direct Payments).
2.4.1 Addressing the lack of service co-ordination and parent liaison

Parents of disabled children described how time consuming, stressful, and difficult it was to access all the different service providers their child needed to see. Some had experienced joint health and social services teams as effective team structures, in particular, due to the fact that the team was geographically co-located in the same building. Multi-disciplinary Child Development Centres have also been set up in a number of areas to improve the co-ordination and accessibility of services to the under-sixes or the under-fours. Although there is considerable local variation, the goal is to make health, education and social services available to children and their parents in a joined up way, geographically situated under one roof. This might be located within a hospital, educational institution or social services building. Some service providers wondered why this joint approach was usually restricted to children up to the ages of three or five. One example of this extended through to the age of 19 for children and young people with HIV, and was said to work well.

Children's Trusts are also now piloting in a number of areas and are designed to build on the framework of Child Development Centres, local Sure Start programmes, Early Years Development and Childcare Partnerships, and Connexions. The Trusts will cover social services, health and education in an attempt to bring greater integration to these services, and unlike the Child Development Centres, they will focus on children across the age range. They will be able to plan, commission, finance and deliver children’s services, including services relating to special educational needs. Both Centres and Trusts should bring a local level coherence to the provision of services to disabled children which should make transitions smoother, although the regional variations in coverage and structure may be problematic for those moving across areas or living in an area without a Centre or Trust.

SEN Regional Partnerships are committees originally set up by DfES as SEN Regional Co-ordination Projects, in 1999 to promote local partnerships to help establish more effective regional co-ordination of special provision and services, in particular for children with low incidence disabilities. The focus has shifted and new national aims have been developed, including the promotion of inclusive practices, with educational inclusion being concerned with a wider group than children have with SEN.

Learning Disability Partnerships were established under the DH’s Valuing People programme. While the focus of the partnerships is on people of all ages with learning disabilities, each must have a Transition Champion with responsibility for taking forward local partnership work supporting young people through transition.

Parents of the disabled children in this study described how they often felt left out of the service delivery decisions that affect their child, and how they felt powerless to change these decisions. Under the SEN and Disability Act (2001) LEAs were required to set up Parent Partnership services to provide help and support to the parents of children with SEN and to offer arrangements for resolving disputes about special
provision. SEN Tribunal procedures have been further streamlined since, and greater emphasis has been placed on the preferences of the child. A new national help line was launched in 2001 for parents of disabled children, provided by Contact a Family with Department of Health funds, to accompany the help directory Taking Care. Where families are made aware of these services this should help with confirming issues of entitlement. The revised SEN Code of Practice does place increased emphasis on both parent and pupil participation, with a new chapter specifically focusing on these issues.

Service providers who had worked in more than one local authority area were aware that there was a great diversity of practice, and felt that they were able to bring good practice learnt in one context to bear in another. The experience of working in more than one local authority and in more than one related sector was felt to be particularly beneficial to improved awareness of good practices and of other sectors’ time-scales, information needs, and practices. Job swaps were suggested as another way of achieving this, especially seconding officers between child and adult disability teams. Such an approach could also be useful in supporting those disabled young people in the area currently approaching transition to adult services.

In Scotland, work is going on in training up professionals about each other’s roles and in developing detailed local and national directories for signposting and ensuring the most appropriate referrals are made first off. This would help to reduce the multiple contacts with, and assessments by, service providers that disabled children would need to undergo, a current problem identified by parents and young people in the study.

2.4.2 Addressing the lack of information and planning for transitions

Young people and their parents sometimes felt that transitions had not been planned for sufficiently in advance, leading to delays and ‘crisis’ transitions. Service providers described the difficulties that lack of information posed for them in providing for disabled young people and their transition into adult services. Since 2002, collection of data on pupil numbers has been conducted by the Pupil Level Annual Schools Census (PLASC). From 2004 the PLASC will include collection of data on categories of Special Educational Need. DfES has now completed consultation over the categories and definitions to use. This system of data collection is designed to estimate current and predict future need, to enable improved planning of SEN inclusiveness policies and adult service capacity.

Involvement of young people in the planning process was recognised by respondents to be important for the transition to run smoothly. One approach to this involved young people attending and contributing to reviews. As part of the publication of the ‘Valuing People: A New Strategy for Learning Disability for the 21st Century’ White Paper, the Government set a target for local agencies that, by 2003, all transition planning for learning-disabled young people should take a person-centred approach. This means planning should start with the individual (not with services) and take account of their wishes and aspirations.
2.4.3 Addressing the loss of services through transition

Parents expressed frustration and concern about whether particular services might be lost when their child moved from one school to another, because the staff or equipment were not available at the new site. Under the Disability Discrimination Act (as amended by the SEN and Disability Act 2001), schools and LEAs have a duty to increase the accessibility of schools to disabled pupils. Policy attention is also being paid to ways in which various skills shortages, which contribute to the delays in getting services which young people experience, can be overcome. One example of this is the DfES focus on recruiting more speech and language therapists and on setting up training courses whereby speech and language therapists work with training teachers to take on more of the delivery of speech and language exercises. There is potentially scope for this to be developed in other areas of the Allied Health Professions. In Scotland for example, 0-19 year olds have a statutory right to Educational Psychological Services, but in practice, 16-19 year olds have not been getting this service, as the provision after school was not in place. Now a new post has been set up to develop a specification for services post-school, and for looking at how this could be best developed for delivery. In time pathfinder local authorities will be developed to explore extending this service up to those aged 24 years.

2.4.4 Addressing the failure to identify service needs

Service providers working with children raised the issue of babies who are hard of hearing being likely to experience delays in obtaining early interventions and support as a result of their impairment not being diagnosed. Since the Audit Commission’s report Fully Equipped came out in 2000, hearing screening has been introduced for new born babies, greatly reducing the likelihood of delays in services being experienced due to unidentified hearing impairments in children. The Government also published new guidance for front-line practitioners in 2003 called Developing Early Interventions/Support Services for Deaf Children and their Families. At the same time, it published new guidance for practitioners supporting all disabled children. Called ‘Together from the Start’, it gave practical guidance about providing multi-agency assessments and early intervention and support.

2.4.5 Addressing service discontinuity and loss at transition into adult services

As briefly outlined in the introduction to this section, there have been a large number of new pieces of legislation and policy aimed at assisting the transition for young people from child services into adult services. The most significant and transition focused of these is the Connexions strategy that was launched in 2000.

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19 The NHS Plan is also focusing on the recruitment of more therapists, including speech and language therapists.

20 These new developments are addressed in detail in the Audit Commission’s Update to Fully Equipped, published in 2003.
The goal of Connexions is to assist the smooth transition from childhood through to adult activities such as education and employment, through the young person working with a Personal Advisor (PA), transition planning, and local level partnership working. Connexions is a support service for all young people aged 13-19 in England. While it provides a universal service, young disabled people are identified as needing particular support. For this group of young people support may be provided, where necessary, until a person’s 25th birthday. The APIR (Assessment Planning Implementation Review) framework developed through Connexions is designed to assist with transition planning, to avoid anxiety about transition, to plan goals for adult life, and to flag up future clients for adult services, thereby avoiding crisis transitions. The Strategy has not yet been fully unrolled, and there is regional variability in most aspects of the programme including: how rolled out the Partnership is, how much of it was happening already, and how contracted out the services are.

There is a data information system, Connexions Customer Information System (CCIS) which is designed to reduce the unnecessary duplication of assessment, ensure the relevant information is accessible to professionals, and to prevent young people from ‘getting lost’. Future progress on smoothing the transition from child to adult services will depend to some extent on the success of the various Connexions partnerships, and to what extent they will be able to address some of the issues listed below:

- The perception held by some service users that the programme is not geared towards disabled young people.

- Whether the variation in how Connexions partnerships are structured (largely contracted out or in-house) will impact on young people moving across partnership areas. (However, having a PA should help in moving from one local authority to another. Guidance has been issued to help PAs in assisting with this transition.)

- Some service providers felt that there was little emphasis on disability issues or training for PAs. It will be important to ensure that PAs are disability aware, and able to advise and signpost towards the range of available services for disabled people such as Direct Payments, Access to Work and Disabled Students’ Allowance.

In Scotland, 13 Inclusiveness Projects managed by Careers Scotland, perform a similar function to Connexions in England, through Personal Advisors, transition planning, and encouraging greater partnership working. The strategy was launched in 2002, and aims to improve the employability and skills of Scottish people,

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21 Under the Learning and Skills Act 2000, Connexions can carry out ‘Section 140’ assessments of young people with SEN statements who are in the last year of compulsory schooling and are intending to go on to Further or Higher Education. The assessments are designed to establish what the young person will need in the new setting.
focusing on increasing the number of young people with additional support needs in further education or training. Each project could choose who their target groups were to be, and so some projects are targeting young people with disabilities more than others. There will be a need for more standardisation in the future as to which client groups are supported so that an issue like training of personal advisors in disability issues can be addressed more centrally and widely. The Additional Support Needs Bill is trying to address how Careers Scotland projects can link better into supporting the transition between child and adult services.

A number of service providers described **new staff roles and transition teams** that had been established to support the move into adult services. These included workers based in schools and social services teams, and the personal advisor role within partnerships such as Connexions and Scottish Inclusiveness Projects. The collation and communication of required information was central to many of these roles, as well as a focus on earlier preparation. One service provider described how she had been able to accurately predict which young people were approaching transition, and with what needs, for the first time this year since the creation of an administrative transition tracking post in her team. The new post involved the collation of data from schools and other service providers working with children in the local authority to create a database of the number of young people approaching transition and the nature of their likely adult service needs. In other teams, no additional staff were appointed but one member was allocated specific responsibility for transitions.

Young people and their parents felt that they knew little about what impact moving into adult services would have on their service provision, and wanted to have the opportunity to be able to plan well in advance. Respondents working with Connexions or as SENCOs said that, in many areas, **transition planning** now started with disabled young people two years, rather than one year, prior to leaving compulsory education. This additional time allowed for a better understanding of young disabled people’s preferences and goals to be developed and an opportunity for them to try out a number of options before leaving school, as well as avoiding crisis transitions. This was felt to be particularly important where an individual’s needs required non-standard services, such as a young person with autism for whom the group context of a day centre would be inappropriate. Young people and their parents, however, highlighted that transition plans were not fixed or static but needed to be regularly reviewed and updated.

The Scottish **BRITE** (Beattie Resources for Inclusiveness in Technology and Education) **Initiative** got underway in August 2001. The Initiative supports young people entering FE colleges in Scotland through the provision of a central Equipment Loan Bank scheme which aims to match users with a range of assistive technologies quickly. The Initiative is described in more detail in Chapter 3 (Section 3.4).
Adult service users felt that **Direct Payments** provided them with more control over the way in which they received their services. The recent extension of Direct Payments to include young people aged 16 and 17 is, therefore, likely to have a beneficial impact not only on their continuity of care through educational transitions, but also with respect to their transfer into adult services. Direct Payments will potentially be able to act as a bridge between child and adult services. The Scottish Executive has allocated funds to a three-year programme promoting awareness and uptake of Direct Payments. It was felt that this needed to be a centrally-run initiative, as it was felt that local service providers sometimes had too ‘paternalistic’ an approach to service provision to be able to promote the scheme themselves. A case could similarly be made for actively promoting Direct Payments with younger service users, in part with the intention of smoothing their transition into adult services.

2.5 Chapter overview

In combining the evidence from the interviews with users and providers, three key areas of difficulty clearly emerge for disabled children and their parents at points of transition:

- difficulties in accessing and delays in getting a service;
- not having a service need met; and
- anxiety about the impact of current and future transitions on service provision.

In this section, findings from the chapter as a whole are reviewed in terms of the barriers to achieving smooth transitions faced by service providers and the facilitators to overcoming these barriers. Issues that were identified as needing policy development are highlighted in Section 2.5.2.

2.5.1 Summary of barriers

Organisational and structural issues

Young people and their parents described the large number of service providers they had to have contact with, how physically scattered and inaccessible these service providers were, and how separately the providers operated from each other. There have been a number of responses to these structural and organisational barriers through improved co-located and closer multi-disciplinary working. These include the establishment of Child Development Centres and Children’s Trusts, which although varying in format at a local level, would not have come about without the centrally-driven initiative and funds. Parents and service providers questioned why most Child Development Centres dealt only with children up to the ages of three or five. In some areas, the model had been extended to deal with young people with a specific disability through to the age of 19. This approach was felt to work well in

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22 See Chapter 5 for a fuller discussion of Direct Payments.
terms of delivering improved continuity of service delivery through different stages of the service user’s childhood.

The parents interviewed in this study often described the confusion and stress they experienced when trying to negotiate services for their children. A centrally-initiated recent response to this issue has been the establishment of independent Parent Partnership Schemes to help parents with dealing with the ‘system’. Likewise, the Connexions Strategy and Scottish Inclusiveness Projects have sought to provide young service users with a personal advisor to assist them in negotiating the system.

Alongside Child Development Centres and Children’s Trusts, health trusts and local authority social services, housing and education departments have been working together to establish multi-disciplinary teams. These have included moves towards, if not permanent co-location, then at least joint surgeries which make services more accessible to young people and their parents. This has been a very important development given the problems service users highlighted with accessibility and co-ordination of services.

Procedural issues

Lack of appropriate data has hindered the informed prediction of future service needs on many levels (nationally, at local authority and health trust level, for schools). This has affected service users in many ways, including schools not having sufficient capacity to accommodate children due to under-estimating the number of required places and adult services having to respond to a child entering adult services as a ‘crisis’ because of lack of forewarning. A recent central initiative to require and structure the collection of data on pupils with special educational needs should go some way to addressing this barrier.

Service users highlighted that service providers were often not able to provide them with information about their entitlement to other services. Service providers were also frustrated by the fact that their colleagues in different departments did not always appreciate their information needs and time scales. For these reasons local initiatives which have encouraged job swaps and secondments to different departments are likely to assist in overcoming this barrier. In addition, work in some areas, including Scotland, has been taking place on training professionals about each other’s roles and in developing detailed directories for sign posting and ensuring the most appropriate referrals are made first off.

Great anxiety was expressed by older young people and their parents about what would happen when they transferred into adult services and activities. Local authority transition teams, or individuals with responsibility for transitions, alongside SENCOs and personal advisors from regional Connexions partnerships, have all been bringing a greater emphasis to transition planning. This was felt by respondents to reassure young service users, as well as to alert service providers to future needs. Service providers felt that it was important that this work continues, and that personal advisors get the training that they need in disability issues and service provision to be able to signpost young service users appropriately.
Pupils, parents and service providers felt that the lack of educational provision through the summer months created a major discontinuity in the provision of care. This was particularly the case where parents and schools had worked well with young people in preparation for their transition into another school, only for much of this preparation to be lost over the summer months. Some nursery and other schools have been able to establish summer sessions with funding from the Lottery and other sources. This was a service which, if extended, both service users and service providers felt would assist pupils with the transition between schools.

Budgetary and funding issues

While general under-resourcing was identified as a barrier to smooth transitions, it was also recognised that the relatively greater under-investment in adult services was a significant factor adversely affecting the transition from child to adult services.

Service users and service providers identified that staff shortages in areas like speech and language therapy has meant that a child moving to a new school runs a very real risk of not having access to this service at the new institution. In recognition of this barrier, central funds have been allocated to initiatives which focus on, for example, training up classroom teachers with the skills to be able to identify particular speech and language problems and to administer designed programmes of treatment in the classroom.

Lack of awareness of specific services and programmes was repeatedly found amongst both service users and service providers. In an attempt to overcome this barrier the Scottish Executive allocated central funds to be used exclusively in promoting the uptake of Direct Payments. A centrally-driven approach such as this was necessary because of the resistance to supporting Direct Payments found locally.

Young people and their parents also felt that if the various service providers they came into contact with worked more jointly, service users might experience a smoother continuation of service provision avoiding, for example, duplication of assessments and multiple visits to different hospitals and social services departments. However, in the interviews with service providers, the fact that funding was not made available to specifically cover the costs of aspects of joint working was repeatedly stressed. It was felt that if local authorities and hospital trusts allocated resources to this activity then this barrier to providing smooth transitions might be addressed.

Variation in the allocation and management of budgets at the LEA level contributed to some areas being better placed to provide continuity of services to the youngest children. A service provider working in a special nursery gave the example of an LEA that permitted the release of funds for special nursery school places and services prior to being statemented, while another neighbouring LEA would not permit funding such services until entitlement to a statement had been agreed.
2.5.2 Issues to consider for policy development

- **There remains a need for improved awareness** amongst disabled young people, their parents, service providers and policy officials about the full range of services and support that is available. Service providers often saw the responsibility for publicity and raising awareness of the availability of particular services as located at national level and as requiring attention at the level of central policy. However, there was also a strong feeling amongst policy officials that the lack of awareness of available support and services amongst disabled people was a local, and a service provider, issue. Issues of lack of awareness emerged at all levels. Allocating central funds to regionally promoting awareness of, and uptake of, available support could be considered, following the model of the Development Funds used to promote uptake of Direct Payments in England and Scotland.

- **Ensuring that young people without a statement are also provided with the services** that they need as they go through transitions clearly emerged as important and as often overlooked at the national and local level. The proposed Scottish approach of dropping the Record of Needs in favour of recognising all children as on a spectrum of special needs is one approach to this problem, although not an approach popular with some parents.23

- **Specific and creative support** for those with autism spectrum disorders, dyslexia, mental health problems and a range of other impairments is needed. Policies which aim to strengthen support for inclusion for these groups needs to be developed, and a fresh approach developed for particular types of needs.

- **Ensuring the success of the Connexions and Scottish Inclusiveness Projects personal advisor role** may require additional support and central intervention to guarantee that sufficient and appropriate disability training is provided. Interviews with young people, parents, service providers and policy officials all stressed the importance of a service co-ordinator or ‘key worker’ type role. The Connexions strategy provides a framework for this to be made available, potentially for every young person over the age of 12 with special needs and every school with children of this age in the country. However, there was some evidence of variation between different regional partnerships in the extent to which personal advisors were trained to respond to the transition needs of young people with disabilities. It will also be important to ensure that the option for disabled people to continue to get personal advisor support, should they need it, up to the age of 25 should be maintained and implemented in practice, and the possibility of it being extended beyond this age considered.

- **Supporting the development of multi-disciplinary teams**, through approaches such as extending Child Development Centres to include children aged six and over and by expanding delivery through geographically co-located services.

23 In their comprehensive review of this issue, ‘SEN – a mainstream issue,’ the Audit Commission did not recommend that this approach be adopted in England.
3 Transitions in further, higher and adult education and training

Chapter summary

Disabled adult service users experienced a variety of different types of transitions in the Further, Higher and adult education sectors. Some disabled people moved into, within or out of education with little or no impact on the continuity of their service provision, but others encountered difficulties. The following factors were identified as relevant to the smoothness of their transitions: support workers (both within and outside of educational institutions, who signposted towards, and provided a link between, service providers); aspects of the education provider (such as their motivation to accommodate needs, capacity for planning, ability to respond to emergencies and the physical environment); the approach of individual LEAs and grant administrators; and the flexibility and transferability of service provision.

A number of barriers were identified by service providers which make achieving smooth educational transitions difficult: budgetary issues (around the differing funding structures for the different educational sectors, lack of clarity over where funding responsibilities lie, and some issues with the structure of Disabled Students’ Allowance (DSA) delivery); failure to plan resulting from non-identification of disabled students prior to starting at an educational establishment; and lack of access to assistive technology centres, equipment banks and assistive technology experts and training.
3.1 Introduction

This chapter focuses on the impact of educational transitions, as experienced by adult service users, and on the provision of services, support and equipment. Adult transitions in education included moving into, within and out of a wide range of different types of activity, from basic skills training in numeracy, literacy and life skills, through to postgraduate research in Higher Education (HE). Central Government policy in this area in recent years has highlighted the need to expand adult basic skills, work-related training, and improve access to Further and Higher education. Within these strategies there has been a focus on service provision to people with a range of different disabilities.

Some aspects of training for work and work experience placements will be discussed here, as well as in the chapter focusing on transitions around employment (Chapter 4). Two other areas covered here also overlap with the focus of other chapters: the transition out of compulsory education and the transition into employment. Given that these two transition points have been identified as particularly significant in terms of their impact on continuity of service provision, it was felt to be appropriate that they be addressed from both the perspective of leaving the previous activity and starting the receiving activity.

This chapter begins by describing the range and nature of educational transitions experienced by the adult disabled service users in the sample, and the factors identified as having an impact on the continuity of their service provision. The chapter then outlines the views of service providers and policy officials on the barriers and facilitators to achieving a smooth transition. Finally, some of the recent national policy initiatives are described in terms of their potential impact on smoothing the continuity of service provision through adult educational transitions.

It should be noted that the research did not aim to investigate any one sector of post-16 education in particular detail or to compare practices across the different countries of Great Britain. Rather, the focus here was to draw out broader barriers and facilitators.

3.2 User views and experiences

3.2.1 Context of adult educational transitions

A number of the adult service users in the sample had recently experienced a change in the provision of education or training they received. They covered the full age range of the sample, from a 17-year-old girl leaving a mainstream sixth form college for a special unit in a Further Education (FE) college, through to a man in his seventies completing an evening class.
The nature of educational provision that service users were moving into, across, or out of varied by a number of criteria, including in terms of:

- the education provider/sector;
- the amount, regularity and timing of provision; and
- the duration of provision.

Educational providers included day care centres, FE and HE Institutions, and other adult education and training providers. These were accessed either at a centre, or through Internet-based learning or postal tuition. Educational transitions included moving between courses run in the day-time, evenings, weekends, and flexible study units that could be taken at any time. Some respondents undertook more than one piece of education or combined education with another activity, such as voluntary or paid employment, work-based training, job search, day centre activities, caring or being ‘retired’. Educational transitions included moving between full-time, part-time and no educational provision, and from short evening classes into longer courses leading to qualifications or Higher Education. The data showed that adult educational transitions were often characterised by progression through a number of steps or stages, for example, a series of short courses preceded one respondent starting a degree at an HE Institution (HEI), and another respondent’s training preceded a work placement.

The subject areas studied by the disabled service users in the sample largely fitted into the following five groups:

- basic life skills, literacy or numeracy;
- Information Technology (IT) training;
- specific work-related or vocational training;
- training in disability issues; and
- general interest, arts and crafts.

Some disabled service users avoided moving into education because they were concerned about the impact that such a transition might have on the services or benefits they received, or because they felt they could not access the services that they would need to be able to undertake the education. Concern about not being able to get the higher level of personal care that attending a venue-based course would require was a disincentive for some service users. Lack of awareness of the Disabled Students’ Allowance (DSA) and other services available to support adults in education were probably further disincentives. Many of these users undertook Internet-based learning at home, and a number of those without a computer expressed the desire to have access to one so that they could pursue Internet-based learning.

Generally, the move into most types of adult education was a ‘chosen’ transition that was not experienced as a ‘crisis’. However, the movement out of education on
completion of a course could be perceived as ‘forced’. In addition, the movement into (especially Higher) education where this coincided with relocation and the need for significant new services and changes in service providers could well be experienced as a ‘crisis’ if it was not sufficiently planned and prepared for.

Reasons for experiencing a change in educational provision varied with the subject area being studied, with the movement into education being prompted by factors such as:

- the advice of a service provider, personal advisor, support group, or due to the requirement of a programme or benefit;
- due to a court order (two respondents were instructed to undergo anger management training);
- for interest or enjoyment; and
- to train or retrain for employment or improved job prospects or life skills.

Personal transitions, such as an improvement in health or children starting at school, often triggered the need or desire to train or retrain for work. One example of this given by a service provider is described below:

John was 50, and had worked as a plumber for 30 years, when he had an accident that left him insufficiently mobile to continue working as a plumber. After negotiations between WorkAble (an education and training provider aimed at preparing disabled people to get into employment) and his employer he began training in IT. This enabled him to apply his expert knowledge in plumbing in an office environment, and remain with his original employer.

The reasons that emerged for service users moving between one education provider and another included:

- progression from compulsory schooling into adult educational provision;
- progression to a higher level of education; and
- because one education provider did not provide the necessary equipment or support to enable the service user to continue.

Difficulties with transport (such as Dial-A-Ride taxis arriving late or the lack of parking spaces accessible to the education centre) and personal care provision, and a decline in health were cited as reasons for moving to a more local or accessible provider or from venue-based provision to Internet learning.
Finally, in addition to some of the reasons given above, disabled service users left an education provider because of:

- the completion of a course;
- a decline in health;
- a lack of equipment or support (including transport and personal care, as well as physical equipment and software);
- realisation that the course was not what was expected or wanted; and
- getting a job or work placement.

The move out of education provision was sometimes effectively prevented by the lack of alternative providers. Some disabled students with learning difficulties had remained at the same day centre for years, despite their desire for progression or change, due to there not being other educational provision or suitable (paid) employment options in the area.

3.2.2 Impacts of educational transitions on service provision

The extent to which transitions in education impacted on service provision depended on the various factors described above. There were a number of key ways in which a transition impacted on service provision:

- an existing and still required service was lost;
- a new service was provided which had not been provided before;
- a new service was required but delayed; and
- a new service was required but not provided.

Existing service lost due to transition

Loss of a pre-existing and still required service when moving into, within, or out of education was often experienced where the educational transition was part of a multiple transition. Some movements in education provision triggered or happened alongside other changes in the lives of disabled service users, for instance, starting or leaving a full-time university course could trigger transitions such as moving home, moving across local authority boundaries, and moving out of or into employment or another day-time activity. For some respondents it was the other transitions, experienced as a result of the educational transition, which actually impacted on the continuity of service provision. Disabled service users sought to prevent multiple transitions resulting from an educational transition, for example, by attending their nearest HEI rather than one that would require them to move.

Few of the disabled service users in the sample reported experiencing their existing service provision being adversely interrupted when they began a course, however service providers did give several examples of where this had happened. Disability officers in FEI and HEI gave the example of loss of existing social and personal care
services often being experienced when the primary service provider had been the family, and the disabled service user leaves the family home to attend an HEI.

Equipment supplied to disabled students through DSA became the property of the student. This greatly eased the transition for respondents leaving HE as the equipment remained with them. Students leaving FE did not get to keep the equipment they used while doing their course, as this remained with the college. This could lead to students starting a course at another FEI where new equipment would have to be ordered if not already available, or undertaking a work placement or voluntary work without any specialist equipment being provided. In FEIs, software and equipment used by disabled students could generally not be removed from the site. This could create ‘mini-transitions’ for students, where access to services was disrupted by physical access. For example, one student had access to specialist equipment while in college, but was not able to use this for homework or for her voluntary work.

**New service was provided**

Two types of new service provision were associated with a disabled person’s move into education. One type was where the transition into education triggered an assessment of needs that highlighted current service requirements, separate from the course of education, that were not being met. For example, one respondent was referred to social services regarding Direct Payments in part as a consequence of an assessment for DSA at an Access Centre. Respondents described how some Disability Officers signposted disabled students to the range of different provision available. The second type of new provision was where a need arose as a result of the new education programme, and was met.

Some of the services provided to students were either inappropriate to their needs or unreliable. For example, one respondent described how his transport provision repeatedly arrived late, undermining his effective participation on the course.

**New service was required but delayed**

Several service users reported experiencing delays in getting a new service that was not ready for the start of term. This was often very stressful for the disabled person, particularly where they had expected that certain services would be provided. Whether the delay in service provision led to the course of education being delayed depended to some extent on what services were affected. Delays in services that were essential for a disabled person to attend at all (such as physical adaptations, transport, and personal care provision) could lead to the education course being changed. Where the delayed services prevented the service user from being able to fully participate in the course (such as classroom support workers, software, and equipment) users sometimes began the course at the allotted time but dropped out later.
New service required but not provided

Sometimes service needs which arose as a result of an educational transition were not met. One piece of equipment that some disabled students starting at a campus institution mentioned was an electric wheelchair. This was a need that they had not anticipated that they would have, but which became apparent to them after starting the course. This was an example of a need that was often not met. However, new service needs not being met was mainly the case where the educational provision was outside of the FE and HE sectors (such as in adult education).

Some respondents had experienced a decline in health during a course of study and found that the education provider was not able to accommodate a new need quickly, effectively, or was simply not able to meet it at all.

3.2.3 Factors influencing the smoothness of adult educational transitions

A range of factors emerged as influencing the smoothness of adult educational transitions. The two case studies below illustrate how some of these factors impacted on disabled people's service needs and service provision. The first example is of a respondent who experienced a relatively smooth handover of service provision and whose new needs were largely being met.

Simon is 38. He was in constant pain, had a frail body and used a wheelchair. A few years ago he had an implant which reduced the pain and has improved his mobility. Two years ago he began to take short courses at a local day centre. He talked with his advocate at the day centre about doing a degree, and his advocate encouraged him and put him in contact with the disability office at his local HEI. A disability officer gave Simon information about his entitlements, both to DSA and to Direct Payments (which he had not been receiving before), and helped him with completing the forms and chasing the LEA. The disability officer ensured he got an independent early needs assessment for DSA. In the first weeks of term the LEA had not finished processing the assessment. The HEI, however, had anticipated this and was able to provide emergency ‘stop gap’ carers from day one to carry books, open heavy doors and take notes. Once the DSA was approved (after negotiation between the HEI disability officer and the LEA grant administrator) Simon received a laptop computer and dictaphone, as well as funding for his required classroom support. None of his existing services had been affected, other than that he is now receiving Direct Payments, which he didn’t have before. He is pleased with Direct Payments as he feels that it has the flexibility to fit in with his college timetable.

This second case study is of a respondent who experienced a disruptive move into education, where her new service needs were not being met.
Mary is 44 and severely sight impaired. She had been at home caring for her three children for the last seven years, and now that the youngest had started school, she wanted to prepare to return to work. Mary was advised about suitable training in the area by an advisor at her local Jobcentre Plus and she began a course in basic computer skills at her local FE college. The advisor informed the college tutor prior to Mary starting that she had a sight impairment. However, only some weeks after the start of the course did the college make an assessment of her needs. Specialist software to magnify her on-screen computer image was sent for.

‘I know it wasn’t necessarily [the college’s] fault but they promised this equipment and each week I’d go in and say ‘is it here yet?’ ‘No you have to be patient at least we’ve ordered it for you.’ ...I was a third way through the course. I wasn’t feeling as if I was doing any work because I was battling with a computer I couldn’t see.’

Mary was never informed that the college had disability officers, and she felt extremely isolated and unhappy in the class, being unable to keep up or follow what was going on. She returned to the Jobcentre Plus advisor, who made contact with the college and arranged for them to provide an in-class support worker. The software did arrive during the second term of the course. However, Mary was so stressed and disillusioned by her experiences up to this point that she dropped out of the course. She now feels that she could not cope with being in a work environment. No crèche or childcare provision was made so she could not attend the college to use the equipment at any times outside of the course. The equipment was located only at the college and she was not allowed to take it home.

These two case studies demonstrate how various factors impact on the smoothness of an educational transition. These factors can be grouped into the following categories:

- role of a support worker;
- approach of the education provider;
- dealing with LEAs and other grant and funding administrators; and
- flexibility and transferability of service provision.

**Role of a support worker**

The presence of an effective support or key worker repeatedly emerged as pivotal in ensuring educational transitions occurred, and occurred smoothly. Such a worker could either be attached to the education provider or attached to some other area of service provision or support. In the smooth transition case study cited above, support worker roles emerged in both places.
Service providers cited by respondents as fulfilling this kind of support role and who were separate from the educational provider, included named social workers, Community Psychiatric Nurses (CPNs), Jobcentre Plus and other advisors, support group workers, and charity-based workers. These workers often helped to trigger the initial movement into education.

Staff based at the educational institution, in particular disability officers\(^{24}\), were generally perceived by respondents as being ‘on their side’. Where the receiving educational provider’s team of disability officers was visible, proactive and motivated, this emerged strongly as a primary factor in the achievement and maintenance of a smooth transition. An indicator of the effectiveness of the disability officers was whether they provided a well-advertised initial ‘reception’ of new students. This was important because, as illustrated by one of the case studies described earlier, some service users had not been aware of the disability officers at their college until they were well into their courses.

Service users who benefited from the support of disability officers cited a range of tasks that they had performed including: being encouraging, providing information about entitlements, aiding application and assessment processes through liaison and chasing (including of other staff at the HEI, LEA administrators, assessors at Access Centres, and social services staff), being proactive in support, and linking to other services. The other key function performed by successful disability officers was enabling a move on to a new provider in terms of providing referrals and signposting to new service providers, careers advisors and employment providers. For both the function of receiving students and signposting them on, disability officers with strong external links with other local providers were well placed.

**Approach of education provider**

The general approach of the educational institution was also found to be an important factor. This was manifest in terms of the education providers’:

- motivation to accommodate needs;
- capacity for planning, preparation and ability to respond to emergencies;
- the special needs focus of the institution; and
- the physical environment.

The educational providers demonstrated variable **motivation** to accommodate disabled students’ changing needs. For example, one respondent’s health deteriorated whereby his hips could not bend beyond a certain angle. He had to drop out of his jewellery making class because the college was not able to provide a suitable table and chair for him to sit at.

\(^{24}\) Known under different names at different institutions, such as the Disability Support Centre or AccessAbility Office.
Where an education provider **prioritised the availability of all required equipment** and service needs for the start of term through preparation and planning, this made an enormous difference. Although the identification or meeting of all service needs prior to the commencement of a course was not always possible, some service users experienced and appreciated the provision of good ‘stop-gap’ measures. ‘Stop-gap’ measures sometimes had to be imaginative, creative and ‘non-standard’.

Whether or not the educational provision accounted for the needs of disabled students was influenced by who the provision was aimed at and what student needs had been anticipated and prepared for in advance by the provider. Some of the educational provision that respondents in the sample had recently started or left was **aimed primarily at students with special educational needs**, and these providers were often better placed to have certain types of equipment, services and support available without delays at the start of the course. Related to this was the extent to which the physical environment of venue-based educational provision had already been made accessible, so that rather than having to react to the individual needs of new students as they joined it was able to accommodate all pupils already.

**Dealing with Local Education Authorities**

Service providers working in HEIs said that disabled service users had found the process of applying for Disabled Students’ Allowance (DSA) smoother since the requirement that all LEAs provide disabled student applicants with a named contact. Having a named contact at the LEA was meant to make it easier and less daunting for service users to check on the progress of their DSA application. Some disabled service users, however, did still describe the great difficulties they had had making contact with their LEA at all, stating that nobody would answer the phone or reply to letters. Problems with delays were magnified by the ‘bottleneck’ that occurred at the start of term, when most disabled students were all getting assessed and applying for services and equipment all at the same time. The recently introduced system of Early Needs Assessment, mentioned in one of the case studies given above, should go some way towards alleviating this problem.

**Flexibility and transferability of service provision**

Disabled students changing between HE courses or leaving an HEI cited the fact that with DSA they had ownership of their equipment and that this was a major factor in the smoothness of their transition. This also allowed them access to equipment at home throughout their course, avoiding the mini-transitions some service users at other education providers experienced where they had access to equipment at the educational setting only. DSA was favourably regarded by respondents as enabling students to obtain the most appropriate equipment, often quickly bought, with clear ownership and which could be located conveniently.

Students found the flexibility of other types of service provision to be important in enabling educational transitions to occur smoothly. Direct Payments was an
example of this. The care component of the Disability Living Allowance was also cited as allowing the ad hoc recruitment of an informal Personal Assistant (PA) to enable one respondent to attend a residential course.

3.3 Service providers’ and policy officials’ views about enabling smooth transitions

Interviews were conducted with professionals working in education and other service sectors to explore the barriers identified as contributing to a lack of continuity of service provision for disabled people, and what might facilitate smoother transitions. These interviews aimed to build on the issues identified by disabled service users. The service providers cited in this chapter worked in basic skills and employment training, day centres, FE colleges and HEIs, although the chapter also draws on the experiences of those in local authority social services, health and education departments. The policy officials referred to here include those working in the Department for Education and Skills, the Department for Work and Pensions, the Department of Health and the Scottish Executive.

The views of service providers and policy officials are reported below under three broad headings: structural barriers, organisational procedural barriers, and funding and budgetary barriers. The chapter then goes on to describe some of the recent national policy developments in this area, and the extent to which these might address some of the issues around continuity of service provision for disabled adults moving into, within and out of education.

3.3.1 Structural barriers and facilitators

Factors relating to organisational structures were intertwined with those of organisational procedures. This section focuses on the barriers identified by service providers that primarily stem from structural causes. These barriers are described below, along with solutions suggested or already employed by respondents. These are grouped under the following categories:

- joint working;
- structure of DSA delivery; and
- structure of educational transitions.

Joint working

Lack of joint working repeatedly emerged as a factor in disruptive transitions. Service providers suggested various ways in which joint working could be improved. Firstly, if the FE or HE institution had a disability focus of which other local agencies were aware, this greatly assisted external service providers in terms of linking with the education provider and referring disabled service users. One service provider said that the disability office in the FE college where he worked had a named social worker. This arrangement worked both in terms of making and receiving referrals,
and had grown up through informal joint working practices. It was felt that FE educational institutions themselves need to take on responsibility for local promotion. A high level of local awareness also made it more likely for education providers to be included in reviews and to be able to make onwards referrals of disabled students to a range of other agencies. Some providers were beginning to work with Connexions partnerships and Scottish Inclusiveness Projects, although there was a general perception that these did not really focus on disability issues.

Sometimes, mainstream educational providers lacked the skills to be able to appropriately support a new student with special needs. One mainstream provider, however, had developed links with disability-specific social services teams in the area. This included involving the specialist support of an autism outreach team in assisting one autistic student arriving at and settling into university. It was noted by some service providers that there was a culture of ‘market economy’ running through post-16 education, as many of the providers in these sectors are competing with each other to recruit the same students and to get increased funding associated with increased student numbers. This could act as a barrier to people working collaboratively on joint enterprises and solutions.

Structure of Disabled Students’ Allowance delivery

Having to liaise with a large number of different LEAs was very time consuming for disability officers in HEIs when negotiating DSA entitlements, as there was great variation in LEA practice. Service providers working in HEIs wanted to see the administration of DSA centralised, but since LEAs have introduced a named contact for each student applicant to contact, it was acknowledged that the current localised nature of the administration is probably better from the user perspective.

Structure of educational transitions

Service users’ experiences indicated that there were often a series of educational transitions, and that educational transitions were sometimes experienced in stages or steps. Where models of educational provision recognised that structure, transitions could often be handled more smoothly. Some service providers recognised that disabled students were likely to move on to another education provider and/or educational sector, and tried to ensure that they prepared students for changes in educational provision. One example of this was an FE Centre that sought to act as a ‘stepping stone’ between special needs and mainstream provision. Another example was of a number of providers who aimed to give disabled students support and advice during the process of application for their next education course.

DSA does not penalise a student if they change courses, and should meet any

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25 Connexions and Scottish Inclusiveness Projects are discussed in more detail in Chapter 2, and alongside other terms used in this report, are defined in the glossary.
additional costs that the new course requires, as well as allowing for retention of existing equipment. Some continuity in service provision, however, was ‘forced’ rather than chosen. In particular, where there was a lack of accessible housing options off-campus, disabled students had to remain on-campus despite the social isolation that that could cause.

3.3.2 Organisational procedural barriers and facilitators

Service providers also faced barriers to delivering smooth transitions that stemmed primarily from, or could be solved through, organisational procedures. Some of these barriers are described below, along with solutions suggested or already employed by respondents. These are grouped under the following categories:

• disclosure of disability and levels of awareness;
• assessments; and
• lack of training and provision.

Disclosure of disability and levels of awareness

Disclosure of disability prior to commencing a course is key in order to enable planning and preparation, and to avoid the autumn ‘bottleneck’ causing delays in assessments and the delivery of services. However, FE and HE service providers explained that some disabled applicants failed to state that they have a disability in advance of starting a course. This may be partly because disabled applicants fear that disclosure will impact negatively on their likelihood of being accepted, and partly because of a lack of awareness of what types of support are available to them and when they need to apply. When applying to an HEI, for instance, students are asked to declare their disability on the same Universities and Colleges Admissions Service (UCAS) form that is seen by admissions officers. The disclosure question is also negatively phrased in terms of having a disability that is likely to impact on their ability to do the course. Service providers highlighted the fact that there need to be other mechanisms for identifying students before they arrive, so that an early assessment of needs can be conducted and as many services as possible put in place.

Identification of disabled students once they have got to university was also an issue. This was due to a number of reasons, including because students may be unaware of their disability (e.g. undiagnosed dyslexia); because they may feel that they will be able to ‘cope’; and because they lack awareness of what services are available to them. Some HEIs were screening all students for dyslexia in order to identify undiagnosed cases, which has proved particularly helpful for mature students. Only some educational providers screen all students, and the cost to the educational institution of obtaining individual dyslexia assessments for its students was felt by providers to be very high. Work is currently going on in this area between DfES and the British Dyslexia Association in developing ‘top-up diagnoses’, where more than

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26 HE students who need dyslexia diagnosis while on their course and are in financial need are eligible to apply to their University access and hardship fund to cover this cost.
two years have transpired since a prospective student was assessed for dyslexia. This should help older prospective students applying for education to establish their eligibility for dyslexia support early on arrival.

Assessments

It was felt that a social service assessment of personal care needs should be carried out by the home local authority, in advance of a student starting a course in another local authority. Not doing this could cause delays at the start of the term. Where such a pre-transition assessment was carried out, sometimes the assessment failed to take account of the fact that the disabled service user was about to leave home and the implications that this would have on the level of services they would require. It was felt that some assessments underestimated the future level of personal care needed because allowance was not fully made for the care currently provided by the family that would need to come from social services. Additional training might be needed to help assessors project how disabled service users’ needs may change when they leave the parental home to live independently.

Lack of training and provision

Service providers felt that if particular types of training and services were available, this would have a positive impact in smoothing transitions. Training in disability issues and in general service provision issues and entitlements was identified as required by LEA awards officers, personal advisors such as those working in Connexions Partnerships and Inclusiveness Projects, disability officers working in the access centres of educational providers in different sectors and others working in educational institutions, and other service providers. A programme of training for LEA administrators and awards officers was being conducted by SKILL27, focusing on improving the support they provide to disabled students moving into HE. The BRITE initiative in Scotland, described later in the chapter, has proved an effective model for linking Access Centres and centralising a bank of expertise for training. This model could work to co-ordinate a range of different types of training and expertise (as well as equipment) on a regional level in England and Wales.

Service providers cited a number of types of services that would ease transitions into education were they widely available. These included providing life skills preparation prior to a young person leaving home, in particular for education. This was felt to be particularly appropriate for young people with autism spectrum disorders, learning difficulties, mental health problems and significant personal care needs. Link courses, designed to give disabled people a flavour of what the education provider is like and in order to provide information about what support services may be available, were also felt to be a good idea for preparing potential students for

27 SKILL: National Bureau for Students with Disabilities. SKILL is a national charity promoting opportunities for young people and adults with any kind of disability in post-16 education, training and employment across the UK.
transition into education. Some education institutions in the FE sector or providing day centre services were able to provide a **rolling programme** of courses and workshops. This meant that students could start at any time, helping to ensure that potential students were not dissuaded by a long wait and avoiding an unnecessarily long transition period. Offering immediate enrolment, service providers outside of the HE sector felt, was particularly helpful where they were providing education to students with learning difficulties or to those who were particularly vulnerable to dropping out. Not interrupting educational programmes with long holidays was also felt to benefit continuity of provision for these groups. Some FE education providers assigned a **personal advisor** to all students with special needs, so that the same person would be able to do the student’s initial assessment, develop a transition plan with them, and be an element of continuity as they progressed through the education programme.

### 3.3.3 Funding and budgetary barriers and facilitators

There were various issues identified by service providers as impacting on continuity of service provision. These included:

- complexity around general funding structures;
- complexity around budget boundaries for equipment and services;
- issues around funding HE students’ needs through DSA; and
- areas that are under resourced.

Inevitably some of these issues related to what made the transition disruptive for service providers rather than for service users.

#### Complexity around general funding structures

Service users entering courses in HE sometimes did not plan for their equipment needs in advance of the course beginning because they did not realise that services at HE are provided in a different way to those at FE. The move between FE and HE has been complicated by the differing funding structures operating in the two sectors. Disability officers working in HEIs felt that officers in FEIs were not sufficiently aware of these differences in funding structure. They felt that FE officers need to ensure that disabled students progressing to HE were made aware earlier on that they would need to apply for funding in HE on an individual basis, and to signpost them towards the availability of an Early Needs Assessment. Colleges providing both FE and HE courses found having the two different funding streams running simultaneously to be somewhat problematic as it meant that different students with similar needs at the same college had different entitlements and had to be dealt with in different ways. In Scotland, these issues are being addressed through proposals for the FE and HE funding councils to be merged, with the intention of creating a
more integrated approach to the whole FE/HE spectrum and funding system.\textsuperscript{28}

Some training and educational institutions were funded from multiple sources, including the Learning and Skills Council (LSC), European Social Fund (ESF), charitable trusts, Jobcentre Plus and other places, and this added to the complexity of financial arrangements. In addition, providers that relied on contracts for providing training allied to New Deal and other programmes found the reapplication process time consuming, and argued that uncertainty regarding whether the contract was to be re-awarded impeded the longer-term development of courses.

Complexity around budget boundaries for equipment and services

As was found to be the case for other types of transition, despite recent developments in this area, issues still arose around how responsibilities were demarcated between different service sectors. This could lead to delays in the provision of services to service users while funding responsibility was agreed. Primary confusion lay between what was the responsibility of education to provide for (through DSA), what was a health and social services responsibility, and what was the responsibility of the educational institution (under the requirements of Part IV of the DDA). One HE disability officer described the confusion regarding funding responsibilities that had arisen regarding a disabled student who needed assistance with going to the toilet while at college. While education accepted funding responsibility for providing care during and between lectures, and health paid for care outside of the study day, such a demarcation was not always clear, for instance when the student wanted to study in the library at the end of the day.

Some service providers in HEIs mentioned that given funding is quicker and easier to get through education (due to the whole process being managed entirely through the DSA application), as much as possible was described in terms of being an educational need. This was done in order to avoid the delays otherwise experienced by service users. Electric wheelchairs to get around campus institutions were described as one item of equipment that seemed to have fallen between the responsibility of different service sectors.

Disabled students outside of the HE sector expressed great frustration over their restricted access to equipment while a student, and their loss of access to equipment on leaving education. Several service providers in both FE and HE sectors and in employment training wanted to see a centrally (regionally) held budget that all the organisations involved with helping disabled people into training for work could draw on, as well as a central bank of equipment available for trying out and for immediate loan. Some service providers attempted on an ad hoc basis to negotiate between the involved agencies for an individual service user to retain a piece of

\textsuperscript{28} The Scottish proposal to merge the Higher and Further Education Councils into a single body, which may go some way towards tackling this problem, is described in the last section of this report.
equipment when moving between, for instance, a place of training and an employer. This was often adversely affected by the existence of complex budgetary boundaries and distinct administrative arrangements and systems. One training provider with no budget for buying equipment took on negotiations between the Learning and Skills Council (LSC) and Access to Work so that a student could retain his equipment when he went on a work placement, and if he remained with the employer, Access to Work would repay the LSC. This was a complex and time-consuming ‘deal’ to broker due to the fact that it had to be negotiated on an individual basis rather than there being a procedure already set up for such a swap, and also because the deal was dependent on later outcomes, i.e. whether or not the disabled service user remained in employment determined whether or not Access to Work would pay for the equipment.

Later in this chapter the Scottish BRITE Initiative is described as an example of a centralised equipment store that gets around some of these issues. It allows students to access and try out various types of equipment, provides equipment on short-term loan where needed to respond to a crisis situation, and can sell equipment to education institutions for longer-term use, as well as provide educational providers with expert advice and training in assistive technology.

Issues around funding HE students’ needs through DSA

Disabled students and service providers in the HE sector described how DSA had a number of advantages for smoothing educational transitions. These included its clear budgetary allowances, ownership, flexibility, and the fact that there is provision for students to be able to change their course without their funding being affected. DSA was cited by HE service providers as a great improvement on the prior funding practice in HE, and service providers raised a number of recent developments in its administration that have further improved the speed and clarity with which it can deliver to students entering HE (such as the introduction of early needs assessment and named contacts in LEAs). There were, however, a number of remaining concerns about DSA that were mentioned by service providers as contributing to delays to, and variation in, service delivery through transitions. These included the following:

- remaining variability between LEAs in interpretation of eligibility criteria; and
- confusion over how far DSA should cover responsibility under the DDA.

LEA level variation in practice had an impact on service users because it created a postcode lottery of entitlement, and negotiations between disability officers and LEA awards officers over this variability could cause delays in the delivery of services. Some LEAs had ‘capped’ resources which students with particular types of disabilities could claim, which goes directly against DfES guidance and makes it difficult for people to be able to predict what they will be entitled to if they move into education. Students with dyslexia were mentioned by some disability officers as subjected to a capped DSA if they came from particular LEAs. This raises the issue of how local practice in supporting transitions, for example LEA grant administration decisions,
can be monitored. One disability officer working in an HEI suggested that there was a need for a central ‘court’ to which decisions that appear to go against DfES guidance could be referred, whilst recognising that such a court might be problematic to operate. DfES policy officials noted that a directive had been issued to LEAs where it became apparent that they were persistently not adhering to DfES guidelines, but that they could not always be aware of local practice and need to allow some scope for local variation.

Another example of LEA variability in the administration of DSA was in terms of what service and equipment needs were recognised as covered. For example, a disability officer described how one LEA agreed to provide a student with both a note taker and a mini-disc recorder, whereas another disabled student with almost identical needs had had his application for both services rejected by his LEA. There was also some variation between LEAs in terms of what education courses were deemed to be DSA eligible. This suggested that some aspects of DFES guidelines around what constitutes a DSA valid course might need to be clarified.

Service providers felt that the fact that disabled students could now have their needs assessed for DSA prior to starting at an HEI had led to a great improvement in overcoming the bottleneck of delays that had resulted from being unable to assess needs until the start of the term. Funds should be released to cover these assessments irrespective of whether the student actually gets into the HEI. However, some LEAs had refused to release funds for assessment prior to the student starting at the HEI, although this might simply be due to the newness of change in policy.

Under-resourced areas
A number of areas of educational service provision were identified by service providers from a range of sectors as under-funded to an extent that contributed to discontinuities in service provision. These included a lack of funds:

- for disability officers to work with careers centres to develop programmes supporting the move out of education and into employment;
- to support disabled service users through work placements, voluntary work and training;
- to provide child care;
- for colleges and training providers to set up equipment pools and carry out outreach work; and
- to provide dyslexia assessments to older students (although this was provided to all students at certain HEIs).

Service providers in HE said that administration of DSA by HEI staff was not properly funded, leading to staff carrying heavy caseloads. One result of this was said to be a reduced amount of time to spend on policy development work, in particular, in response to the requirements of Part IV of the Disability Discrimination Act. Not all of the time they spend working with disabled students is charged to their DSA
accounts as this would ‘bankrupt’ students. They felt that providing students with an individual record of their DSA account would better prepare them for balancing their service provision across the years of their study.

There was a general commitment amongst service providers in educational institutions of all sectors, to try to always provide a service they perceived to be necessary, irrespective of whether funds were available. This sometimes meant that disability officers did not put down all the time they spent with students to their DSA accounts and disability teams sometimes went over budget. If they were not able to provide a service they perceived a disabled student to need, then, as mentioned previously, some service providers in educational settings adopted an advocacy role to try to obtain funds or equipment from another source, such as through applying for hardship loans from the educational institution.

### 3.4 Recent developments in national policy and initiatives

There has been a large amount of new legislation and initiatives in recent years that have addressed disability issues in relation to basic skills, special needs, adult education and training, lifelong learning and aspects of Further, and Higher Education. These have included the Education White Paper Learning to Succeed (which focused on post-16 education and training), the Learning and Skills Act (which introduced the Learning and Skill Council), and the Special Educational Needs and Disability Act (which extended the remit of the Disability Discrimination Act, Part 4, to include educational institutions). There has been the establishment of regional and cross-departmental working groups to tackle the clarification of personal social and education funding responsibilities, joint working and other issues affecting disabled people moving into education. Policy developments in two areas of educational provision are described under the following headings:

- Disabled Students’ Allowance; and
- the BRITE Initiative.

#### Disabled Students’ Allowance

One area of policy development affecting the move into HE has been changes to DSA. There has been a shift in emphasis in the policy work around DSA from development to improving the administration of DSA in terms of its speed and consistency. Work done on speeding up the delivery of DSA to avoid delays in receiving support and equipment has included permitting Early Needs Assessment and ensuring that LEAs provide prospective students with a named contact to process their DSA application. This focus on administrative issues has been necessary due to the large increase in the number and amount of DSA claims, and has taken on board many of the recommendations made by the recent SKILL review.
of DSA administration. Greater support is now being provided for disabled postgraduate students, thereby easing their transition into HE. Work is also being done on improving the quality of assessments that should reduce variability between LEAs regarding what is funded under DSA. LEAs have a new role, with reduction in workload that is meant to allow them time to pursue this, to actually promote HE and funding available to disabled students.

The BRITE initiative

Service providers sometimes felt that it was difficult to identify the most appropriate equipment for service users at the start of the term. This was because there was little opportunity for students to try out the range of different tools and because some service providers lacked expertise in what tools are available. Since 2001, the Scottish Executive has provided funding for the BRITE (Beattie Resources for Inclusiveness in Technology and Education) initiative to look at assistive technology and how it can be used to improve access to FE. BRITE works closely with the three Scottish Access Centres, under a ‘hub and spoke’ model where each of the 50 FE colleges in the country nominate a BRITE Link Person. This person receives training at BRITE, so that each college has one assistive technology expert who in turn, trains the other staff at the college. A website and ‘virtual staffroom’ have been established so that staff from FE colleges across Scotland, can obtain information and discuss specific issues. As part of the initiative, an assistive technology work station is being placed in every college. BRITE has also established an equipment bank with a range of high-tech and low-tech software and hardware. Students can visit the centre to test out equipment, which can then be loaned out to the college. Although the scheme currently focuses only on the FE sector, service providers from Jobcentre Plus, LEAs, and other training providers have expressed interest in being involved.

3.5 Chapter overview

In pulling together the findings from the interviews with disabled students and service providers, three broad areas of difficulty emerge for service users moving into, within or out of education:

• lack of awareness of the availability of support;
• delays in getting a service; and
• (in some education sectors) not having a service need met.

29 http://www.dfes.gov.uk/studentsupport/dsa_.shtml

30 The initial achievements of the BRITE initiative’s work on transitions, as well as other aspects of the Beattie National Action Group, are described in Inclusiveness - being implemented, Potential - being realised: The Beattie National Action Group Progress Report and Future Priorities. 2003, Edinburgh: The Stationery Office.
This final section reviews evidence from the chapter as a whole, to explore the barriers to delivering smooth transitions. Areas identified as requiring consideration for policy development are described at the end of the chapter.

### 3.5.1 Summary of barriers

#### Organisational and structural issues

Service users’ educational experiences often involved a series of transitions, and educational transitions that were made up of stages or steps. Where models of educational provision recognised that structure, transitions could often be handled more smoothly. Service providers felt that educational provision needed to be planned with this progression in mind, including support for the development of link courses and ‘stepping stone’ educational providers that bridged special needs and mainstream provision. Service users with learning difficulties felt that they were prevented from moving out of educational day centres because there were few alternative local opportunities for them to progress into. Service providers felt that there needed to be a greater policy emphasis on meeting this need.

Some service providers working in education, felt that there were cultural barriers to joint working. In particular, the culture of ‘market economy’ that exists between different adult, HE and FE institutions competing for funding and status, can act as a barrier to effective joint working between different educational providers operating in the same sector.

LEA level variation in DSA administration had an impact on service users entering education because it created a postcode lottery of entitlement, and negotiations between disability officers and LEA awards officers over this variability, could cause delays in the delivery of services. There was a feeling amongst service providers (as well as service users) that training in disability issues and DSA eligibility criteria for LEA grants administrators, would be appropriate, and work of this sort is currently being undertaken by SKILL.

Service users described the difficulties that they faced when leaving education and preparing to enter employment. Disability officers felt that this transition could be smoothed if funds were made available to support increased joint working between disability officers, careers centres and other providers, to develop programmes supporting this move. Similarly, it was felt that the transition into education could be made smoother if various services were amended, or offered, to prospective students prior to their leaving home. These included life skills preparation, and a personal care assessment of their needs which took full account of the level of family care provision that would have to be met by social services.

#### Procedural issues

Service providers highlighted how the lack of disclosure of disability prior to the commencement of a course, inhibited their ability to plan services. It was felt that this failure sometimes stemmed from the procedural mechanism of requesting
disability status on the same application form that is seen by application assessors. Service providers highlighted that there need to be other mechanisms for identifying disabled students prior to day one of a course, so that an early assessment of needs can be conducted and as many services as possible put in place.

Disabled people wanting to enter education, are equally affected by the barriers that prevent other people entering education and would, therefore, benefit from general barriers being tackled. An example of this was the lack of access to childcare provision, which, if more widely offered on a local basis, would facilitate disabled people entering education.

Service providers in educational institutions sometimes felt that their ability to support students entering education was sometimes hindered by the fact that the students themselves were not aware of their own disability. Dyslexia screening of all students entering an educational institution was one way of addressing a key aspect of this barrier. Other service providers felt that the cost of obtaining individual dyslexia assessments, e.g. from an Access Centre, was prohibitive.

**Budgetary and funding issues**

Some service providers felt that the complexity of having differing funding structures operating in the HE and the FE sectors was an additional burden that added to the delays experienced by some disabled students. The fact that students did not have to apply for funds on an individual basis in FE contributed to the fact that they were not aware that they would need to apply in such a way when they started at HE.

Delays also resulted from confusion over where funding responsibility lies, for example, what was the responsibility of education (through DSA), what was a health and social services’ responsibility, and what was the responsibility of the educational institution (under the requirements of Part IV of the DDA). Greater central guidance was required for HEIs regarding what their responsibilities are towards their disabled students, and work between social services, education and health needs to continue.

Disabled students outside the HE sector expressed great frustration over their restricted access to equipment while a student, and their loss of access to equipment on leaving education. Several service providers in different education sectors and employment training, wanted to see a regionally-held budget that all the organisations involved with helping disabled people into training for work, could draw on, as well as a central bank of equipment available for trying out equipment and for immediate loan. Some service providers attempted, on an ad hoc basis, to negotiate between the involved agencies for an individual service provider to retain a piece of equipment when moving between, for instance, a place of training and an employer. This was often adversely affected by the existence of complex budgetary boundaries and distinct administrative arrangements and systems.
3.5.2 Issues to consider for policy development

A range of areas emerged as requiring further policy development. These are discussed under the following headings:

- supporting the move out of education; and
- other areas for policy development.

Supporting the move out of education

While there has been a strong policy focus on supporting the move out of compulsory education, service providers felt that similar attention was not given to supporting the transition out of further, higher or adult, education, and into, in particular, employment. There was a feeling that on a national level, no one was taking a policy lead on this move, and that at a local level, it was unclear where responsibility for advising, supporting, or sign posting at this stage, should lie. This contributed to a lack of awareness amongst disabled students about employment programmes and services such as Access to Work and New Deal for Disabled People (NDDP), and social services delivery options such as Direct Payments (where students were not already in receipt of this). Service providers suggested a number of ways in which this transition could be better addressed by tackling the following issues:

- lack of clarity around vocational practice criteria;
- lack of awareness of future employment and social services options; and
- lack of options for students with learning difficulties.

Vocational practice criteria

Firstly, it was felt that an earlier focus on preparation for leaving an educational programme for employment was needed. For example, some service users were unable to establish, until after graduation from a particular vocational programme, whether they would actually be permitted to practice in that field. It was felt that blanket regulations dictating, for example, the level of eyesight required to practice as an ophthalmologist, would be undesirable. However, if the official bodies were able to provide guidelines or advise on individual cases prior to students starting a course, then disabled students would be better able to plan for employment. The regulations and codes of practice regarding employment, occupation, qualifying and trade organisations, are currently being consulted on by the Disability Rights Commission, and this might result in the resolution of some of these issues (and of those around vocational work experience).

31 Responsibility has variously been described by different respondents as that of Access to Work, the individual education providers, careers advice services, disability officers, and HEFCE.
Awareness of future employment and social services options

Service providers in educational institutions accepted that improved signposting was required in order to ensure that young disabled people were aware of their options after leaving education, in particular, what their service provision entitlements were. Access to Work was cited as an example of a scheme, which, if left to Jobcentre Plus to publicise, awareness amongst disabled students would remain low. Some disability officers in academic institutions adopted the role of advisors on availability of services such as Direct Payments, but others felt that they did not have sufficient capacity to successfully take on this role. Service providers in educational settings felt that that funding was required to set up a proper programme of guidance and support with the Careers department, and for younger service users, the involvement of Connexions or Inclusiveness Projects. This could include involvement of organisations such as the Employers’ Forum on Disability and working closely with ‘receiver’ providers, such as advisors at Jobcentre Plus.

Developing options for students with learning difficulties

As mentioned previously, the lack of employment and other options available for students with learning difficulties and disabilities, often prevented a transition out of education and day centre activities, despite this being a transition that some of them wanted to make. The Beattie National Action Group in Scotland, has expanded the model of supported employment to provide more support to employers taking on young people, including those with learning difficulties, moving into employment from education. This approach could, potentially, be a model used to support older people with learning difficulties leaving education and day centre activities, where this is a transition that they want to make. This is an issue that needs to be tackled by education providers, as well as by employers and service providers in the employment sector.

Other areas for policy development

Improving awareness

A greater emphasis needs to be placed on new ways of promoting or advertising services and discussion needs to take place regarding where responsibility for such promotion should lie (i.e. what combination of activity at the local and national level). Although DfES do publish posters and circulate booklets and many HEI and FEI open days publicise the availability of support, further work on improving awareness seems to be required.

Disability specific policies

- A coherent dyslexia policy needs to be developed, including discussion of extending dyslexia screening across adult education; and reducing the cost and improving the accessibility of dyslexia screening.

- The development of specific strategies for supporting the move into education among people with a range of different impairments, including Autism Spectrum Disorders and mental health problems (this could include developing the links between education providers and NHS provision).
Expertise centres and equipment banks
Consider expanding aspects of the Beattie Commission’s work in establishing training in assistive technology to FE providers and equipment banks to England and Wales, and within Scotland, to beyond FE.

Disabled Students’ Allowance
- Develop mechanisms for the improved central monitoring and checking of LEA grant administration practice.
- Continue development work on improving and harmonising assessments of need for DSA.
- Funding councils could be more prescriptive to FEIs and HEIs about what their obligations are under the DDA.

Developing closer working
- Disability specific outreach teams could have their remit expanded to work with providing occasional specialist support to ease transition into adult, further and higher education. Local specialist teams could be encouraged and supported to do more staff training with various mainstream and special needs education providers.
- Consider ways of bringing FE and HE policy and funding closer together.

Widening Participation Strategy
There is potentially scope for an increased focus on the needs of disabled students within the Higher Education Funding Council for England’s (HEFCE) Widening Participation Strategy (which consists of activities to target the individual groups that HEIs have identified as under-represented and ensure their success).
Chapter summary

The decision to make an employment transition often involved the individual gauging whether the change would make financial sense and whether they would receive adequate service provision to take up employment. Their responses to both of these issues were shaped by their level of access to information and awareness of services. Amongst the factors that enabled a smooth transition, was having an employer who was supportive in terms of attitude or resources, and service providers operating effective signposting and referral systems.

However, there was not always evidence of joint working between service providers and this could lead to a disabled person experiencing delays in receiving a service, or not receiving a service at all. Reasons for this included the way in which a service was organised (e.g. operating during office hours only, so that it was not accessible to a disabled person working full-time), or due to conflicting procedures (e.g. meeting the requirements of Health and Safety legislation whilst operating within the Data Protection guidelines could make information sharing difficult), or budgetary boundaries (e.g. Access to Work’s ‘pay and reclaim’ funding arrangements which could lead to employers being reluctant to allow an employee to take a piece of equipment to their new workplace until they were reimbursed). Barriers could, therefore, be created by central Government policy design, local practice, or through a combination of both.
4.1 Introduction

In this chapter we explore issues surrounding transitions involving employment. The chapter begins by presenting the context within which individuals decide to make an employment-related transition, the impact that this transition can have on service provision, and the factors that enable a smooth transition. It then moves on to consider service providers' and policy officials' views about current policies, procedures and other factors that facilitate or hinder transitions, and concludes with a discussion of issues to consider in terms of developing policies that would facilitate smoother transitions.

The chapter is based on interviews with disabled people who have made a transition into, or within, employment, with service providers involved in enabling those transitions, and with policy officials primarily from the Department for Work and Pensions (DWP) but also from the Department for Transport and the Department of Health.

4.2 User views and experiences

4.2.1 Context of making an employment transition

Three types of employment transition were identified:

- people who were (re)entering the employment market;
- people who were already in work and were having to make changes in order to remain in work; and
- people who were moving out of employment.

The level of choice in making these transitions varied. Within the first group – entering the employment market – there are the ‘newcomers’ to the employment world. These people were likely to have been in education or training and exercised choice to progress into the labour market. This group also included those who were returning to work after ill health or for other reasons such as family commitments – for them there was also an element of choice in their return. However, for the second group – those already in work – there was more of a sense of forced transition, in other words their health or impairment had deteriorated and in order to remain in their current post or in work, they had to make changes such as adapt their workstation to accommodate a wheelchair or transfer to another area of work, for example, to an office-based job rather than work on the shop floor. Among the final

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Our sample did not include people who were making a transition out of employment. However, discussion with service providers shed some light on the types of issues that individuals making such a transition are likely to face. This information is only used to complete the picture of employment transitions but is not discussed in detail.
Apart from the role that health played in making the transition, a key reason cited for a change was to be nearer home and to cut down on travelling distance. In other words, transport difficulties (such as time and distance issues and finding accessible transport) were a critical factor in their decision.

When deciding to make an employment transition, an individual was faced with a number of issues:

- The first was about gauging whether it would be worth it financially. For those bringing up a family or those who were caring for others, the concerns about losing benefits and receiving adequate pay to make the transition worthwhile were paramount. This anxiety was picked up by service providers who spoke of the need to better publicise the range of ‘in-work’ benefits that an individual may still be eligible for, even when in paid employment.

- Another dilemma was around the consequences that a change may have on their current provision. For those making a transition from education into employment, it could entail ending a long-standing relationship with a service provider, for example, with university-based Disability Advisers and having to form new ones, for example with Disability Employment Advisers (DEAs). For those moving within the labour market, there could be the fear of not being able to transfer existing provision from one job to another, for example, if there was confusion over ownership of equipment. And where changing job involved moving to a different part of the country, the possibility of variations in service eligibility criteria or the lack of a particular provision, for example, accessible housing, brought additional uncertainties.

- An employment transition[^33] could require an increase in service provision. For example, an individual might need more, or different, types of transport or equipment, or the transition may produce a brand new need, for example a visually impaired person may require support with familiarisation with a new vicinity. And with any such increases or changes, there will be the question of whether the service providers and the new employer will understand their disability and its impact on the job; and provide the support and/or equipment needed to do the job. For example, for a person with mental health problems, concerns may not be so much around providing physical adaptations to the workplace but more about ensuring flexibility, such as whether they can take time off or work part-time if they become ill, whether the employer will maintain contact whilst they are off ill, or whether the organisation is open to reducing stress at work.

[^33]: From here on in ‘employment transition’ means transition into, or within, employment.
4.2.2 Impacts of making a transition

Making an employment transition usually involved undergoing an assessment. Whilst assessments were considered a vital part of the process for calculating service provision, it was repeat assessments or those perceived as being repeat assessments (e.g. re-calculating fares to work for the same journey where a disabled person had returned to work after a lengthy break), that caused irritation amongst service users. Repeat assessments were tolerated where it was clear at the outset that there was going to be an increase, or change, in provision. Such a case involved a person who as a result of changing job, had to use taxis rather than public transport and consequently, required a change of wheelchair to facilitate her change of transportation. Another involved someone who was transferring from a part-time to a full-time post and, therefore, required their personal assistant to increase their working hours to accommodate new tasks and routine, which required a re-assessment.

However, where there was an expectation or perception that there was likely to be no alteration in service provision, having to undergo another assessment was most unpopular. At best, it was viewed as the service providers ‘creating a job for themselves’ and at worst, as one person who had to go through repeat assessments for an on-going service stated, ‘degrading having to answer such offensive questions as I am still disabled’. As discussed later, it could be that the service provision (e.g. IT equipment) remains the same but the service provider or source of funding changes (e.g. from the Learning and Skills Council providing a computer for a work placement to Access to Work providing it in the workplace). However, these are ‘behind the scene’ activities and it is upon what the public sees that they judge the need for further assessment.

Similarly, from a service provider view, the need for a further assessment may be determined by changing requirements, given changes in impairment or in work circumstances, but a service user may not perceive this in the same way. And it may be an information issue – that the user may not be clear about what they are being assessed for or why – that is at the root of the problem.

An employment transition did not necessarily occasion a change in service provision but where changes did follow, their impacts were wide ranging. They included:

- becoming a service user;
- losing existing service provision;
- need for increased provision (being identified but not delivered);
- change of service provider;
- change in type of provision; and
- delays in receiving service provision.
Becoming a service user

Some people became service users as a result of making a transition. For example, some of those making a transition from unemployment to employment found themselves undergoing assessments, applying for funding, and receiving service provision for the first time.

Losing existing service provision

In some cases, an employment transition could cause the loss of existing service provision, such as adaptations made to a workstation that could not be transferred to a new place of work. The transition could also affect non-employment-related provision. For example, a person transferring from a part-time to a full-time job reported discovering that she could no longer receive home help services because the hours of service were incompatible with her hours of employment, namely, that it started after she left for work and ended before she returned, and weekends were not an option. Conversely, for another person, leaving full-time work had meant that home help and other services had become more accessible.

Need for increased provision

Sometimes a transition entailed an increase in the quantity of (some) existing provision, for example, a person who moved from part-time to full-time work noted requiring increased personal assistant hours. However, the same person needed a decrease in fares to work contribution because the new place of work was nearer home. In other words, the change in quantity of provision required was not always simply an issue of more, or less, service. As illustrated by this example, there could be a range of impacts of a transition on provision requirements. There was a further dimension to increased need being identified, and that was when it was not being met, despite being formally assessed as necessary. This was usually a matter of resources, and was likely to result in a delay (discussed overleaf) in receiving a service rather than not receiving anything at all.

Change of service provider

The impact of having a change in service provider varied. For example, if the change involved a change of personnel, the change was obvious and one of the consequences was having to form a relationship with a new professional. Such a situation could be faced by a person making a transition from HE to employment, whereby they used to deal with a university disability adviser and now have to negotiate with a DEA. However, a change of funder may not be so obvious, especially if a limited reassessment is required and the same provision continues.

Change in type of provision

A transition could not only cause a change in quantity of provision but also in the type of provision. For example, a transfer to a workplace further away from home, meant for one wheelchair user, that he required a different type of wheelchair to be able to use a taxi rather than a bus.
Delays in receiving service provision

No matter what impact a transition had made to service provision, be it to increase it, decrease it, or remove it, delays in receiving services and/or equipment was a common experience. Access to Work users reported that its funding arrangements (where the employer has to initially pay for equipment but which can be reclaimed from Access to Work) had in some instances resulted in the old employer refusing to allow them to take the equipment with them to a new job until the old employer had been reimbursed.

Avoiding transition

Given the sometimes negative consequences of making an employment transition, some respondents reported deciding not to make the transition. For those who were returning to a job from which they had taken a break, there was the anxiety that the support they were receiving would no longer be there. Others were reluctant to alter their circumstances for the fear of ‘losing a good package’. Such misgivings could prove to be unfounded and were often driven by lack of information and awareness of services. However, there were instances where negative past experiences, for example, losing existing services or feeling unsupported through a transition, resulted in a future transition being cancelled, as the case below illustrates. In this instance it was a difficult transition in education that had put the person off making a transition into employment.

Sophie, who is visually impaired from birth, lives with her three young children. She does not use any equipment or receive any services at the moment but used to have talking books and get help with shopping from her local authority. She has been doing some voluntary work and decided that whilst her youngest child was still part-time at school, she would investigate her employment options so that she would be ready to work as soon as her child went to school full-time. To this end, she has undertaken a range of courses at local colleges and through career services. Her experiences were not very positive – equipment arriving well into the term in her first course, not at all in her second course, and feeling that the onus had been on herself to find out what support and services were available, for example, when she enrolled at college, she was not told that there was a course disability officer. She now feels that she would not be able to cope with work ‘because of everything I came up against’ while doing the courses and, therefore, has decided not to make the transition into employment.
4.2.3 Factors influencing smoothness of a transition

A range of factors appear to influence how smooth a transition is for the service user. These are discussed next and are grouped under the following headings:

- no change of service provider;
- attitude and approach of individual user;
- key person;
- attitude and approach of employer; and
- signposting and referral system.

No change of service provider

Not having to change service provider usually meant no (or minimal) re-assessment, alterations in set up or additional paperwork. All of these things could ease the transition into, or within, employment. The way in which the service was delivered (e.g. whether it was locally or centrally administered) was critical in this process. If it was service provision from a national/central source with uniform eligibility criteria, assessment processes, and model of service delivery (such as Access to Work) then a certain degree of transferability was possible. Also where the service user continued to manage the service, e.g. Direct Payments, this also resulted in smooth transitions because, in effect, the service provider was not changing, it remained as the service user. In such cases, the service user could, for example, simply take their existing personal assistant to their new job. Of course, where individuals bypassed statutory services completely and, for example, purchased their own IT equipment they were consequently free to keep it and transfer it with them through changes in employment to training to college, and so on.

Attitude and approach of individual user

The personal resources of the individual also played a vital role in the smoothness of a transition. Whilst some were hesitant in seeking support, others adopted a much more proactive approach: investigating options, challenging assessments and complaining about delays and errors. Typically, these individuals tended to be active in ‘disability circles’ with a high level of awareness of disability policies and issues, or indeed have been or are currently employed in such fields. It followed that these were the type of people who were using Direct Payments to manage their services and as noted above, this was one of the factors that enabled a constant service provider and, therefore, smoother transition. It is worth qualifying this, however, by noting that irrespective of the intentions of an individual, personal resources could be influenced by the individual’s state of health.

Key person

Rather than ‘doing the chasing around themselves’, some respondents reported developing a relationship with a ‘key person’ who took on that function. This was
not necessarily part of that key person’s responsibilities or they may not even be employed in the service area that the disabled person needed to deal with. Such a case involved a woman who reported that she asked her occupational therapist, who had assisted with adaptations to her home, to help her with dealing with DEAs. There was not a strong feeling about who this person should be (e.g. whether it should be a social services employee or someone based in a jobcentre). But it was clear that whoever took on this role should be in a position that allowed them to link with all relevant agencies in order to play a co-ordinating role.

**Attitude and approach of employer**

The level of employer awareness about disability issues and policies also influenced the ease with which a transition was completed, for example, previous experience of employing disabled people helped 34. However, lack of previous experience, or indeed disability awareness did not always prevent an employer aiding a transition. As the case below illustrates, sometimes it was simply an issue of resources.

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Ruth has had polio from birth and her mobility is deteriorating. She lives alone and has two grown up children who live locally. She is a wheelchair user, receives Disability Living Allowance (DLA) and has had a range of adaptations made to her home that were funded by her local authority. She works full-time for a large multi-national company and has been in her current job for two years. For her new job, she moved ‘from a very modern building that was fully accessible to one that is in an isolated location...and they’d never come across disabled people before’. At her interview, she told them what adaptations she would need and they responded within a couple of days. She has been provided with a space next to the building to park her car, they have put suitable steps and handrails outside the building, grab rails in the bathroom, and carpeting on the office floor where it was slippery or it would hurt if she fell. They provided everything that she requested, all equipment and adaptations were funded by her employer, there was no external OT advice or assessment involved or requested, ‘it was just a case of choose a carpet and we’ll put it down for you’. She is always pointing out to her employer that ‘they can actually get grants for these sorts of adaptations, but at the moment they’ve always just said, ‘well, they haven’t been that expensive”’. However, the adaptations have only been made to the immediate space that she works in, and not to the head office – ‘But I also go down to head office a lot, in fact I’m going down there tomorrow for three days and again, when I go to head office there’s problems because they don’t have any access at all for disabled people’.

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Further it was not just a matter of the employer being able to meet current needs but if the disabled person wished to stay there (or the employer wanted to retain them), then they would also need to think about whether the employer could accommodate the disabled person’s changing/increasing needs.

**Signposting and referral systems**

A shared knowledge amongst service providers of each other’s roles and remits also helped towards making smooth transitions because it meant that providers were able to signpost to appropriate services and make timely referrals. For example, DEAs referred people to Access to Work, or Occupational Therapists suggested Direct Payments, which meant that it was not left to the individual to do the searching and chasing around. Dependable signposting and referral systems became even more critical where a transition involved crossing a local authority boundary because of service users’ possible lack of familiarity with the organisation of services in the new area.

### 4.2.4 Summary of user perspective

The research identified three types of transition: those who were (re)entering the employment market, those who were already in work and were having to make changes in order to remain in work, and those who were moving out of employment. Choice-led transitions were likely to be found in the first group (e.g. moving into employment from education or training), whilst deterioration in health or impairment had usually triggered transitions made by the other two groups. The decision to make an employment transition often involved the individual gauging whether the change would make financial sense; what impact it may have on their current service provision; and whether they would receive adequate provision to take up employment. Their responses to all of these issues were likely to be shaped by their level of access to information and awareness of services. A variety of impacts could follow a transition, including becoming a service user for the first time; losing or gaining service provision; need being identified but not being met; change in service provider or service type; and delays in receiving service provision. Given the possible negative consequences of making a transition, some disabled people were deterred from doing so. However, a smooth transition was likely if it did not involve a change of service provider; or the employer was supportive in terms of attitude or resources; or the individual had personal resources (e.g. was proactive); or had a ‘key person’ to be proactive on their behalf. Service providers operating effective signposting and referral systems also helped to facilitate a smooth transition, and this appeared especially critical when the transition involved moving across a local authority boundary.
4.3 Service providers’ and policy officials’ views about enabling smooth transitions

This section draws on interviews carried out with service providers in the field of employment, including DEAs, Access to Work staff, and staff from voluntary and private agencies who are contracted by statutory organisations to deliver work-related services such as Direct Payments. It also presents material from interviews with policy officials from the Department for Work and Pensions, the Department of Health and the Department for Transport. The section addresses the difficulties in making an employment transition raised by service users and examines service providers’ and policy officials’ views about the role played in those difficulties in terms of barriers and facilitators created by:

- national policy;
- organisation structural issues;
- organisation procedural issues; and
- financial/budgetary boundaries.

4.3.1 National policy barriers and facilitators

There is a tranche of Government programmes that seeks to assist the transition into, and within, employment for disabled people including New Deal for Disabled People (NDDP), Work Preparation, WORKSTEP and Access to Work. This section opens with a discussion of how the aims and objectives of national policies and initiatives can present barriers to smooth transitions. It then moves on to address issues around dealing with employers in implementing such policies, and ends by looking at the role of transport as an enabler of employment transitions.

Aims and objectives of programmes and initiatives

A range of Government employment programmes and initiatives that aim to enable disabled people to make employment transitions, were noted by respondents. However, the extent to which these programmes and initiatives’ aims and objectives were considered to facilitate a transition varied.

Programmes that were job-outcome-focused, whereby entry into work was the primary objective, were questioned by some service providers. An example of this was NDDP. There was a concern that NDDP’s condition of payment to job brokers on job entry could lead to the more ‘hard to place’ disabled person being overlooked. Some service providers queried whether the aim of NDDP was to target the disabled community and assist them to make the transition into employment (in which case they could target hard to place individuals and invest in a long term plan that would lead to employment) or whether the aim was to reduce numbers on Incapacity Benefit (in which case they should target less hard to place individuals) who, in their view, in some cases may have entered the labour market without the intervention of the programme. However, a job-outcome-focused programme was not without
merit. Indeed, a recent study\textsuperscript{35} looking at NDDP, reported that job broker managers believed that the principle of outcome funding could ‘promote greater creativity in service design and promotion’.

Initiatives that recognised the importance of pre-work preparation, retention and sustainability through on-going support, were popular with service providers. An example mentioned of an initiative that recognised pre-work as being critical to a smooth transition, was Work Preparation. It allowed individuals to experience what a particular job would be like through ‘job tasters’ in a work environment, offered opportunities to learn new skills and update old ones, and provided help to build confidence. This was seen as being useful not only for the disabled person, but also for the service providers, for example, by offering the DEA an opportunity to assess the barriers there may be for the individual, such as hours of work, tasks involved, journey to work, and so on.

However, there was a perception among service providers and policy officials that such programmes could be viewed as being static because some people ‘did not seem to leave’ and there could be no job outcome. They explained that for some disabled people remaining in a programme, such as WORKSTEP, was an active process and that such programmes should be assessed in terms of job input rather than job outcome.

In terms of ensuring on-going support, which was another ingredient noted by service providers for a smooth employment transition, the use of ‘tracking systems’ (used by some providers running, for example, Work Preparation programmes) was commended. Tracking systems aim to check, in the early stages of a placement, whether any new support needs have emerged or existing ones changed, and to monitor the sustainability of the acquired job. This may explain the frustration expressed by some Access to Work staff who, although required to support employers to act on Access to Work recommendations, cannot compel an employer to do so.

Programmes that adopted a ‘blanket’ approach (in other words one that aimed to meet a range of needs with a single solution) also came in for criticism from some service providers and policy officials. They maintained that some styles of programme could deliberately, or inadvertently, exclude certain people. For example, a ‘support yourself’ approach (that placed the onus for monitoring progress on the disabled person, or where communication was via the telephone) was felt to be of limited help to a person, for example, with mental health problems, who might require a more pro-active role to be taken by the provider, or have access to drop-in facilities. It was argued that service provision needed to address the range of impairments and offer an equally wide range of provision.

Dealing with employers

An important aspect of enabling disabled people to make an employment transition was the continuous exercise of identifying new, and maintaining existing, organisations and companies as employers. Comments were made by service providers that some aspects of legislation or national policy made this relationship problematic. For example, the policy of Access to Work for the employer to make the initial outlay for equipment, even though it could be claimed back, could sometimes discourage existing, or potential, employers. On the other hand, WORKSTEP was cited by service providers as an example of an initiative that enjoyed a good relationship with employers because its idea of internal progression (which means that the disabled person is no longer supported by WORKSTEP but there is no need for them to move out of the company where they have been a supported employee) makes business sense for employers because they can retain people already trained in the job. It also provides stability for the disabled person who has progressed into unsupported work. However, it should be noted that service providers identified confusion among some employers about internal progression. They believed that once the disabled person was unsupported by WORKSTEP, the employer would have to lose a trained worker, which of course brought with it resentment.

More generally, service providers felt that where programmes were seen as, or were, linked to economic initiatives rather than, for example, to Social Services (in other words not to the caring/supporting part of local authorities) they were easier to implement with private sector agencies because employers saw them as being more in tune with their approach.

Transport issues

The availability and accessibility of transport was identified by service users as an important factor in their consideration about making an employment transition. The centrality of transport as an enabler in facilitating a transition was picked up by service providers and policy officials and as one service provider put it ‘you can get all the jobs in the world but if you can’t get to work, what’s the point?’. The overall policy direction for transport is to reduce dependency on special transport and increase usage of public transport. To this end, aspects of the Disability Discrimination Act (DDA) promote accessible transport. However, a shortcoming identified by some service providers and policy officials was that so far, in most cases, the DDA had only made transport more physically accessible by providing, for example, wheelchair accessibility on new buses. But to be truly accessible (and enable employment transitions) it also had to offer routes to areas that disabled people needed to get to do their jobs such as colleges and industrial estates. This gap, to some degree, is being filled by Fares to Work (one strand of Access to Work support), which aims to provide funding for an individual’s transport needs to enable them to do paid work. However, it should be noted that service providers (and service users) commented that the requirement to claim costs incurred during work (as opposed to getting to and from work) separately, could make claiming less straightforward for those whose job involved extensive travel during work.
A further point worth noting regarding Fares to Work was its relatively low profile reported by service providers. They cited cases where transport issues had prevented people making an employment transition. There was also evidence of the lack of awareness leading to duplication of services and, thus, waste of resources, for example, a local provider, who was unaware of Fares to Work had established a service with similar aims.

### 4.3.2 Organisational structural barriers and facilitators

There was evidence of the way a service was structured influencing the service providers’ ability to facilitate a smooth transition. The location of a service within an organisation and the nature of structure (e.g. specialist versus generalist) sometimes produced barriers, such as delays in receiving services or not knowing what services are available, and these are discussed below.

#### Location of service within an organisation

The location of a service within an organisational structure could be critical to whether the service provider was ‘in the loop’, be it in terms of information, communication or decision-making processes. For example, Access to Work is delivered from regional administrative bases rather than at a more local level. This geographical location means that it is not coterminous with social services disability teams, nor located alongside Jobcentre Plus administrative bases: it was, therefore, viewed by some service providers as being isolated from the ‘loop’ of information and decision-making. A recurring point of concern was the practice of having to refer cases above a certain amount of money to regional level, which not only caused delays, but was considered by some service providers as having to consult management whose primary function was not to provide disability services.

#### Nature of organisational structure

Organisational structures that were considered by some service providers to dilute specialisms were felt to have disadvantages. The relatively recent creation of Jobcentre Plus was given as an example of a reduction in specialism: some DEAs, for example, reported being asked to take on cases from New Deal for Lone Parents and other ‘disadvantaged’ groups, which are not disability-focused. Their perception was that the broadening of role could reduce the amount of input for those individuals who require more staff time, and it could, thus, potentially result in not finding work or making a less successful transition (the issue of generalist versus specialist roles is discussed further in Chapter 6). In this respect, the tight focus of Access to Work was seen as a positive by providers. This meant that its focus did not become overshadowed or weakened by, for example, also trying to obtain employment or deal with social and domestic issues, and furthermore, individuals could access the service directly. This was considered to make it an efficient service.

On the other hand, Access to Work’s tight remit of dealing with employment and not wider areas such as domestic or social needs, meant that staff were not routinely invited to case conferences or reviews (held by, for example, social services) and
consequently would not know what adaptations, services or equipment had been provided regarding, for example, home, that could be transferred to an employment setting. This limited contact could go some way to explaining the relatively low levels of awareness of Access to Work not only among disabled people\textsuperscript{36} but also among non-Jobcentre Plus service providers\textsuperscript{37}. This appeared to have two main consequences. First, there was evidence of obvious routes of referrals not being used, and second, the lack of understanding of Access to Work’s role meant that its staff sometimes unjustifiably received complaints (e.g. about delays in receiving services). In other words, it was not always understood by service users and service providers that Access to Work’s responsibility is to \textbf{fund} and not to \textbf{provide} services.

However, regular national network meetings involving Access to Work business centre managers are addressing issues of improving linkages, including how to work with other agencies. A result of this could be to raise the profile of Access to Work and consequently, improve referral routes. At the same time, routes for claiming Access to Work directly have been developed, so that referral via a DEA or other professional is not necessary, and this may reduce the significance of a referral role.

\subsection*{4.3.3 Organisational procedural barriers and facilitators}

Organisational procedures were identified as another reason why service users experienced delays in receiving a service, or indeed not receiving a service at all. Procedures were developed by organisations to deliver their services. The differing \textbf{aims and objectives} of services sometimes produced conflicting procedures that made it difficult for service providers to work jointly, and as noted earlier the lack of joint working could create barriers to smooth transitions. Limited joint working sometimes led to the \textbf{lack of awareness} of each other’s roles and a reluctance to \textbf{share information}, both potentially causing delays for the disabled person in receiving services or not receiving services at all. These issues are explored next.

\section*{Organisational aims and objectives}

As would be expected given the range of services, providers worked to differing aims and objectives. However, even for those working with the same broad remit (in this case employment), there could be factions, for example, those with work preparation goals having different aims and objectives to those with a brief to find employment.

In order to meet their objectives, service providers worked to their own organisation’s procedures. These were not always complimentary, and were indeed, in some cases,


in conflict with each other. The following case illustrates this point. It involved a referral made by a community mental health team to a DEA. To help its staff meet the Data Protection Act, the community mental health team had designed its own procedural guidelines, which stated what information about a client could be shared with other service providers, and the member of staff had made the referral accordingly. However, the DEA receiving that referral believed that he did not receive adequate information about the health of the individual to enable him to place them in employment, citing health and safety legislation.

He went on further to claim that based on ‘bitter past experience’, had he progressed to make the placement and it had proven unsuccessful due to a reason that the DEA had not made the employer aware of (because he himself was not in possession of the information), it could not only jeopardise that placement but also the relationship with that employer and, consequently, future placements. In such a case, both service providers were operating within their organisation’s procedures but it was the disabled person who was likely to experience an unsuccessful transition. Such tensions were not restricted to relationships between statutory bodies but were also present amongst voluntary agencies and between the statutory and the voluntary sector.

On a positive note there was evidence of organisations agreeing and working to joint procedures that resulted in a more effective and efficient service. One such case involved procedures that allowed DEAs to independently produce action plans for what they termed ‘mainstream’ disabilities, but where a situation involved a disability in which DEAs had limited knowledge, they were required to involve an expert in the assessment process.

Awareness of other services

Among some service providers there was a lack of awareness of other service providers’ roles and remits and, in some cases, even their existence. This was evident even within a shared service area. At times, the lack of understanding of each other’s roles led to inappropriate referrals or no referral at all being made. An example of the former, involved a DEA who noted receiving referrals from community mental health teams for individuals who she considered were not ready for work. The lack of relationship meant that she felt unsupported and unable to seek help or guidance in an area where she had no expertise. In terms of not referring a person to a service that they need, this became more critical where a provider was dependent on another provider for people accessing their service, for example, DEAs acting as a gateway to a range of rehabilitation and training opportunities, as well as employment options.

However, there were cases where service providers were taking proactive steps. These included promoting their own service to other service providers, for example, a WORKSTEP provider described how, although their route of referral was via DEAs, they advised other agencies, such as Sure Start, of vacancies. Another example involved learning about and using expertise from other providers. One such case
entailed inviting staff responsible for the Disability Living Allowance to regular DEA team meetings to explain the workings of the Allowance.

Shared information

There was evidence of the lack of shared information between professionals about the user. Some service providers believed that, on occasions, the reason for withholding information was not to look after the interest of the user nor to meet the requirements of the Data Protection Act, but was more to do with what could be described as ‘professional territorialism’. However, the situation usually appeared to be due to the lack of understanding of other service providers’ roles (as explained already previously) and, consequently, not appreciating the information that they require to carry out their function. As noted earlier, a transition across a local authority boundary often brought with it a change of service provider. Where the new and old service providers operated incompatible management information systems, the flow of information became increasingly problematic. This intensified the need for case conferences that brought service providers together, without which a complete picture of what services an individual was receiving or required was not always possible to obtain.

4.3.4 Funding and budgetary barriers and facilitators

An employment transition could lead to service users having to deal with a new service provider or a number of providers. This could be limited to new providers within the employment sector or, indeed, also involve providers from other sectors such as health, housing or education. In such situations, the lack of joint working and co-ordination between the service providers and the subsequent delays could create a barrier to a smooth transition. One reason for the lack of joint working was related to funding. Concerns were raised about how the levels of funding can interact with systematic budget boundaries created by the ways in which funding is organised, or how budgets are structured or accessed that can prevent joint working and lead to discontinuity in services. These issues are discussed next.

Some service providers felt able to meet only their statutory obligations, i.e. deliver their day-to-day front-line services. They reported lacking the resources to participate fully in additional activities such as networking, or attending joint meetings, in other words it affected their capacity for joint working. This was evident even with colleagues in related fields, for example, some DEAs explained that they only had the time for daily dealing with clients and not for networking with colleagues to, for example, follow up initiatives suggested by the recent Green Paper38, such as, to reduce numbers of people claiming Incapacity Benefit.

Inadequate funding was not a key issue for all service providers, for example, aspects of Access to Work’s budget arrangements allowed an element of choice and

encouraged employment transitions. There was evidence that cost was not always a major factor in its decisions. In some cases, if a certain piece of equipment enabled an individual to enter or remain in the labour market, it was funded, even if the outlay outweighed the returns, for example, in terms of earnings or duration of the employment taken. However, it must be borne in mind that current Access to Work policy requires the employer to make the initial outlay and, therefore, it is possible that the financial state of the employer may influence the smoothness of a transition rather than the favourable budget arrangements operated by Access to Work. Some service providers maintained that having to make an initial outlay was likely to have a greater consequence for certain types of employers and, therefore, deter them from considering employing disabled people. They argued that, for example, smaller businesses or those that had never had disabled employees, and may also, therefore, be unaware of the service, were considered unlikely to approach Access to Work. In contrast, larger, and perhaps more established employers of disabled people, were perceived by service providers to be more likely to be aware of Access to Work, and better able to shift their resources to ‘pay and reclaim’. In other words, their view was that type of employer could shape whether Access to Work’s funding process creates a barrier to a smooth transition.

However, Access to Work cost approval conditions seem perhaps less helpful for those making an in-work transition, for example, moving from one job to another within a company, compared to starting work for a new employer. This is because policy requires the employer to make a contribution if the disabled person has been with them for more than six weeks. Also, there is a £300 threshold, so employers with an existing member of staff who needs special equipment or adaptation cannot make a claim until the cost is above this level, and then they receive 80% of approved costs.

4.4 Recent developments in national policy and initiatives

There is an on-going agenda of national policies and initiatives emerging from central Government that attempt to enable disabled people to move into, and remain in, employment. Below we present a couple of examples of recent such initiatives.

The Job Retention and Rehabilitation Pilot (JRRP) is a joint initiative between the Department for Work and Pensions and the Department of Health. It is running in a number of areas around the UK from April 2003 for a period of two years. It involves a randomised trial of interventions designed to help those people who are off work because of ill health or a disability, to stay in employment. Three models of interventions are to be tested and evaluated: help in the workplace, help with health services or a combined intervention involving both health and workplace services (there will also be a control group).
The Incapacity Benefits Pilot (Incapacity Benefit pilots) is a DWP-led initiative. It involves new Incapacity Benefit customers taking part in a work-focused interview eight weeks into their claim (rather than at the beginning), and for those screened in a series of five further monthly mandatory Work Focused Interviews (WFI) if they are still claiming Incapacity Benefit at the eight weeks point. A part of the WFls is to draw up an action plan that identifies the steps required to reach long-term employment goals. For those who do successfully return to work, a specialist adviser remains in contact and provides in-work support in the early period of employment where deemed necessary.

4.5 Chapter overview

The two main problems that service users making an employment transition reported facing were:

- not getting the services/equipment that they need (including losing services that they used to receive);
- delays in getting what they need.

In this section we pull together the evidence presented in the chapter and reflect on:

- the key barriers that create these problems under the following headings:
  - organisational issues;
  - procedural issues; and
  - budgetary issues;
- the origins of these barriers.

Finally, Section 4.5.2 notes issues requiring consideration for policy development.

4.5.1 Summary of barriers

One explanation given by service providers as to why a disabled person making an employment transition could be confronted with delays or non-receipt of services, was the unhelpful aspects of the policy framework within which services operated. Another explanation was the lack of joint working among service providers. The lack of joint working usually meant that there were low levels of awareness among providers of each other’s services. The consequences of this included: providers not being in a position to let disabled people know about all their options; not making timely referrals to other services; or sometimes not making a referral at all.

It is important to note that these points are based on the perceptions of the service providers. In other words, it may be the case that they are operating under the misapprehension that a policy requires them to organise and deliver their services in a particular way, where in reality, policy is not that prescriptive. However, in terms of the end result – i.e. a disabled person making an employment transition experiencing a delay in receiving a service or not receiving a service at all – the points are just as critical.
The barriers identified will be summarised under the following headings:

- organisational barriers;
- procedural barriers; and
- budgetary barriers.

**Organisational barriers**

There were occasions when the way in which a policy required a service to be organised could lead to a disabled person facing a difficult transition, in other words its structural location was unhelpful. For example, Access to Work not being coterminous with social services disability teams, nor located alongside Jobcentre Plus administrative bases, could affect its profile and, therefore, consideration among other service providers as a service appropriate for a disabled person making an employment transition.

Another example of policy organising a service in a way that some service providers believed led to delays in disabled people receiving a service, was the perceived broadening of the DEA role. DEAs maintained that being required to take on cases from New Deal for Lone Parents and other ‘disadvantaged’ groups, reduced their resources for working with disabled people, such that their ‘specialism’ was reduced.

In addition to feeling that policy design sometimes resulted in services being arranged in a way that was obstructive to delivery, some saw the lack of clarity of the aims of policies as creating difficulties. The confusion could lead to a situation where service providers felt unconfident about *how to organise services*. An example of this was NDDP. They questioned whether its aim was to target the disabled community and assist them to make the transition into employment or whether the aim was to reduce numbers on Incapacity Benefit. The lack of clarity was making it difficult for them to correctly target the programme and, therefore, causing delays for some disabled people.

The way in which services were organised at delivery point could also be unhelpful in ensuring timely delivery or receipt of services. Incompatible hours of service (which could mean that a disabled person in full-time work was unable to access a service that operated within office hours only), for example, was one case of how a service’s organisation can create barriers.

**Procedural barriers**

It was usual for service providers to design procedures to enable them to implement policy. However, there were cases where policies appeared to have conflicting aims that consequently produced conflicting procedures, which could cause delays in service delivery. For example, social workers operating within procedural guidelines designed to meet the Data Protection Act sometimes found it difficult to share client information with DEAs who were required to follow procedures to meet health and safety legislation.
It was also necessary for organisations to design procedures that would assist them to meet their own service objectives. On occasions this could lead to organisations working to conflicting procedural guidelines that also caused delays in service delivery. Examples of such practice included operating incompatible management information systems and procedural guidelines that did not lend themselves to information sharing.

**Budgetary barriers**

Budgetary arrangements set out in Government programmes could on occasions make it difficult for providers to ensure that a disabled person received a timely service. For example, Access to Work’s funding arrangements (where the employer has to initially pay for equipment but which can be reclaimed from Access to Work) could make the old employer reluctant to allow a disabled person to take a piece of equipment with them to a new job until they had been reimbursed by Access to Work.

Another unhelpful aspect of budgets was that they underestimated the cost of joint working. Repeatedly, services providers claimed that their financial situation meant that they were not in a position to engage fully in joint working but were only able to meet their statutory obligations. Such a climate was not favourable to raising awareness among the providers of the wide range of services available, and consequently, informing disabled people or making referrals could be adversely affected.

4.5.2 **Issues to consider for policy development**

- **Improving availability of, and access to, information to disabled people:** there was a general lack of information available to disabled people about the range of services that existed and how to access them. This meant that sometimes decisions about transitions were made on incomplete information. Information, for example, that provides a clear steer on what an individual’s options are and what the consequences of each option are on that individual’s existing service provision, need to be available and accessible. This would enable more informed choices to be made and transitions to be more trouble free.

- **Demonstrating that programmes are built on experience:** service providers reported being regularly faced with a range of programmes from central Government with little evidence of how they were building on existing programmes. ‘Innovation’ was seen to sometimes come at the expense of experience, and, therefore, produced a climate of ‘programme fatigue’ where service providers began to question ‘why should this one work?’. Therefore, new programmes need to document how they are drawing on the positive and negative experiences of existing programmes/initiatives, and how they fit into the existing array of employment-related programmes/initiatives.
• **Making greater use of management information**: an effective management information system should allow mapping of the target audience profile, monitoring of progress, and evaluating outcomes and impact. Such systems would enable, for example, more meaningful budget monitoring that could answer questions such as ‘does Access to Work’s increasing budget mean that the number of needs being met is increasing or the type of need is more expensive (e.g. a ramp would be a one-off payment, whereas a support worker or taxi to work will be a working lifetime commitment)?’

• **Working with companies that have no experience of employing disabled people**: such companies would require a greater input to understand what is expected of them and what they can expect from the programme deliverer (for example setting out the legislative framework within which the companies would have to operate such as the implications of the DDA, and directing them to routes for advice/guidance such as the Disability Rights Commission). Also, this avenue provides an opportunity to raise awareness of programmes such as Access to Work.

• **Further addressing the issue of transport**: need to consider making public transport truly accessible by addressing the issue of routes.

• **Exploring ways of encouraging joint working**: generally, and specifically tackling the situation in terms of joint working between services that do not have shared statutory priorities, and in Scotland where joint working with Jobcentre Plus, NDDP, etc can be difficult because although these initiatives cover Scotland, they are not located within the Scottish Executive but at Whitehall.

• **Widening the scope of existing programmes/initiatives**: for example, consider addressing area of ‘Access to Voluntary Work’ and ‘Access to Work Experience’.

• **Considering ideas for new programmes**: for example, designing programmes that equip disabled people with skills to become self-employed.
Chapter summary

When disabled people are moving home, or changing their home support in some way, the transition can go smoothly but they can also encounter a range of difficulties. The following features would help create smoother transitions: co-ordination of the process, including of assessments, and greater information and communication about the process; reduction in delays in getting adaptations or receiving services; increased awareness of what is available, involving greater pro-active work by service providers, alongside more choice and control for the user to determine what they feel is a suitable, or appropriate, service/adaptation; more provision of initial support for making adjustments to a new geographical area or new living situation.

A range of things were identified that can make or have made it difficult for service providers to enable people make smooth transitions: aspects of service provision fixed by legislation: for example the rules of the Disabled Facilities Grant; organisational barriers between social services, housing and health sectors, leading to lack of shared understandings, and limited joint planning in relation to any particular user, as well as low awareness of other services; limited resource levels hindering the ability of staff to work closely with other agencies, and to be pro-active in their approach to the service user. Some of this operated at more of a national level, whereas other aspects were at a more local level, relating to the allocation of resources by a local authority. Not being able to transfer equipment between local authorities or be guaranteed a similar care package can act as a significant disincentive to users wanting to move.
5.1 Introduction

In this chapter, we will look at the type of transitions that people make in relation to their home and housing situation. There are a number of transitions covered, the main types being:

- move from one house to another;
- change in type of accommodation – e.g. from independent living to a supported living environment, or vice versa;
- move from one local authority area to another;
- move out of hospital and back home, or to new accommodation; and
- changes in level of impairment or health condition, or in personal or family circumstances, leading to changes in service need at home; and preventing an unwanted transition as a result.

These different types of transition have implications for a number of different service areas, the main ones addressed in this chapter are:

- provision of housing adaptations; and
- provision of support and equipment in the home.

In addressing the issues in this chapter, we have drawn on interviews with disabled service users who have experienced the transitions listed above (Section 5.2). We have also drawn on interviews with service providers in local areas, in the fields of housing, health and social services, and with policy officials from the Office of the Deputy Prime Minister (ODPM) and Department of Health (DH) (Section 5.3).

5.2 User views and experiences

This section draws on interviews carried out among disabled people with some experience of making a transition in the area of housing or home situation. It identifies problems faced by users and reports possible explanations for these problems (drawing on users’ perspectives). However, the information from users is often limited in terms of explaining why something happened the way it did, often the user is unaware of what happened ‘behind the scenes’. Section 5.3 attempts to fill this gap, by presenting views from service providers about the barriers to enabling smooth transitions for users generally (although not for the specific users in this section).

5.2.1 Reasons for changes in housing situation

There was a range of reasons behind the changed housing or home situation among the service users we spoke to. On the whole, the sort of housing transitions people spoke about were ones they had initiated themselves, although there were examples of people who had moved out of residential accommodation because it
had been closed down. The following were the main contexts for the housing moves:

- A move towards a more ‘supported’ situation: this was generally the result of a deterioration in someone’s health condition or impairment, for example, reduced mobility or increased frailty. This included moving into sheltered or supported accommodation, or into accessible housing.

- A move towards a less ‘supported’ situation: this happened where people moved out of supported accommodation or away from their parental home, and into their own home.

- A move of house driven largely by personal reasons unrelated to impairment or health: for example, moving to get away from an offensive neighbour, start a new job, be nearer friends or family, or get a more comfortable or larger house.

- A move out of long-stay hospital and into new accommodation, for example, following a period as a psychiatric in-patient.

How these moves impacted on service need depended on a number of different factors, of which changes in impairment or health were just one aspect. Changes in service need were also shaped by the degree to which an informal carer (i.e. partner or family) was providing support at home before and after the move. At the same time, the user’s view about their level of service need was also shaped by their attitude towards receiving help and support versus being self-sufficient, and their expectations of service provision.

5.2.2 Impacts of moving home on service provision

There were three main types of potentially negative impact that people faced when they moved home:

- loss of an existing service, or lack of provision of a new service that is now required (for example, because of deterioration of disabling condition, or because of new accommodation type);

- delays in receiving a service (including delays brought about through waiting to have an assessment, or through the delay in transfer of administrative records, for example, housing benefit, other state benefits and medical records);

- change in service provider or type of service provided.

Of course, moving house does not necessarily occasion any changes in service provision. Some people experienced smooth transitions on moving, where their provision continued uninterrupted, or the adaptation they required was dealt with immediately. The factors underlying what makes a transition more or less smooth are explored in the next section. In addition, some people gained extra services as a result of the housing transition they made; this happened when someone moved to supported accommodation with a range of different support and equipment services (some of which they may not have been previously assessed as needing).
The case studies below illustrate some of the more difficult issues that service users can face when making this type of transition.

Mary and her husband Phil, both in their late 50s, wanted to move area so that they could live in a bungalow with a garden, and be ‘more independent’. Both Mary and Phil have fairly severe visual impairments, Phil also has a hearing impairment and Mary has diabetes and a mobility impairment. When living in their original home, they had a guide dog, a health visitor and diabetes nurse, and used talking newspapers and voluntary transport.

When they moved area, they no longer had a guide dog (because the dog had been ‘retired’ just before they moved) and felt it would be difficult to get one because they did not know the area themselves in order to teach the dog (also the waiting list was long). Their medical records took a long time to transfer, and they did not get any of their previous health services at home. They did not know why. They did continue to receive talking newspapers, as they were just able to give a change of address for delivery. The worst impact of the move was being unable to cope with an unfamiliar area and inaccessible pedestrian environment, which had a dramatic impact on Mary’s confidence and mental health, and meant that she felt unable to chase around to get services. A little over a year later they moved back to their original area, to within a few streets of their old home.

Mike is in his late thirties and lives with his wife and three children. He has a back injury which means he uses a wheelchair and has severe pain. The family wanted to move from their previous house because the accommodation was upstairs and he was barely able to go out, and it ‘was driving me nuts’. He has recently moved to a new house provided by the council and a local housing association, and adapted for him under the Disabled Facilities Grant. Finding out about the house ‘was pure luck’, when someone from his day centre got in touch with someone from the council (otherwise it may have been much longer before he moved). The adaptations took over a year to complete, and would probably have taken much longer without the intervention of the day centre worker, who ‘kept the ball rolling’. Mike was frustrated by the length of time it took, and the bureaucracy involved, and did not understand why this had been necessary. However, he is now ‘thrilled’ with his new house.
The following is an example of a smooth transition.

Jean moved with her husband to sheltered accommodation several months ago, she is in her late sixties. She has cardiovascular problems and impaired mobility. Jean’s son initiated their move by contacting the council housing department and getting the necessary forms to fill in. No one came to assess their needs, but Jean thinks that the housing department spoke to social services and to their GP about them. Their GP applied to social services for a new bath lift (which they could not take with them because they had moved between council districts), within two weeks social services did a telephone assessment, and within another two weeks the bath lift had arrived. Someone from social services also visited to assess their need for grab rails in the property. The couple feel that the transition went very smoothly, and they appear to have a good knowledge of who to contact for what, as well as having good help from their GP who was a key person for them in getting things done.

Given these potential impacts when moving accommodation, it is not surprising that some service users expressed reluctance about moving. Anxiety about losing an existing support package was a significant barrier for some people to making this kind of transition.

5.2.3 Factors influencing smoothness of transition

In this section, we look at the main factors that appear to influence how smooth a transition is for the service user – what made similar transitions easy for some and more difficult for others. These are identified from the user perspective rather than what service providers say (see Section 5.3). The factors are grouped under the following headings:

- variability in service provision across and within, local authority areas;
- circumstantial factors;
- dealing with service providers; and
- attitude and approach of user and provider.

Variability in service provision across and within, local authority areas

There were two issues raised here that could lead to different experiences: firstly, variation within a local authority depending on the approach of individual staff, and variation between local authorities as a result of application of different eligibility criteria.

It was clear, and not surprising, that from a user point of view the ease of making a transition and getting the services required, was dependent on the quality of the individual worker(s) responsible for the move. Some people felt their particular housing officer or occupational therapist was excellent and always went out of their
way to make sure things were done on time, was always available, and did things to a high standard. Others were disappointed with the service they received and put it down to an individual who never returned calls, and offered what was seen as inappropriate help or equipment.

People moving, or thinking of moving, between local authority areas, were aware that local authorities had different eligibility criteria for assessments and different attitudes towards disability, for example in the extent to which they involved the service user in decisions about their support package or not. This point was echoed in our interviews among service providers, for example, that local authorities might differ in the number of hours of personal assistance they assessed a user as requiring under a Direct Payments package (for example, some may be prepared to fund help for someone in carrying out leisure activities, whereas others would not).

Circumstantial factors

Three main factors linked to the user’s circumstances had a clear bearing on the way the transition worked out. Firstly, the distance somebody moved affected the extent to which they could transfer their existing services with them – clearly someone moving across authority boundaries was not able to transfer an existing service, and someone moving a significant distance within an authority might retain a right to the use of that service (for example, a home help service), but may find it provided by a different agency and, therefore, perhaps in a somewhat different way. However, a very local move could often be made with no change in service. This was also dependent on the transferability of the particular service itself. A support worker, for example, could perhaps easily continue working with a user, whereas adaptations to the home are clearly not transferable from one house to another (for example, ramps or grab rails that have been installed in the home). A further key issue for people moving to a new area was how to find out about services available in that area (this was also sometimes true for people who had lived in an area for a long time).

The second factor that seemed to affect the impact of the transition was the type or severity of impairment. A person with learning difficulties with a support worker may find the transition between homes easier to carry out than someone with a mobility impairment requiring home adaptations. The example given in the first case study shows how having a visual impairment can have a particular impact when moving to a new area because it is very difficult to become familiar with the environment of the new area. Similarly, delays in service provision may be easier to bear depending on the impact they have on everyday life – waiting for a shower to be installed could, for example, be less disruptive than not being able to move easily around the home at all (because of the need for grab rails or stair lifts). Interviews with professionals suggested that someone with multiple impairments or complex needs may be more likely to find themselves involved with a number of different social service ‘teams’, therefore, possibly adding to the complexity of their transition. On the other hand, one service provider suggested that people with milder impairments or conditions may find it harder to get the services they needed because they fitted less neatly into service provision structures.
Finally, their personal and family circumstances could affect how easy it was for someone to move. Family members could be valuable in enabling a transition to happen smoothly (see below); however, this was not always the case, and some professionals reported that family members sometimes made it difficult for a young person to leave home because they were reluctant to let them go. If someone was moving away from an environment where family had provided the bulk of their care and support, it was important that this would be replaced by professional support when they moved.

Dealing with service providers

There were a number of factors relating to the process of dealing with service providers in these sectors that varied between respondents, and appeared to have a significant impact on how they experienced the transition between homes. The main issues that appeared to cause difficulties were:

- insufficient information for the user during the process of the transition, including poor communication about what was happening and when. As a result users could find the process confusing and impersonal;

- contact with a number of different professionals (housing, social services and health professionals, as well as their GP), including having a number of different assessments: users found having to go through assessment processes degrading and felt them to be unnecessary. They could not see why information could not be collected or obtained via, for example, a GP who knew their condition; and

- involvement of a third party co-ordinator: there were mixed views about the role a co-ordinating body or individual could play. Some felt they were very useful in ‘keeping the ball rolling’ (see next point); others who felt they could manage this role themselves, felt it to be an additional layer of bureaucracy and duplication of provision. One family felt they had done all the work in setting up their home adaptation (finding a builder and an architect), and then resented having to pay £2,000 (which was taken out of their grant) to a charity (working under contract to local authority) for ‘doing very little’.

One of the factors that appeared to shape a smoother transition was the existence of some kind of ‘advocate’ who could help manage the process and chase things up on the user’s behalf. This might be a partner or other family member, a GP or a support worker, or a representative from a disability organisation:

‘...it’s a good idea to have an independent person, away from the social services and things ... to keep everybody going rather than you having to phone up every two or three days to see if this piece of paper has been passed around, because you just get downhearted. [worker] proved invaluable; she kept the ball rolling.’

Male, thirties, wheelchair user

Related to this, it appeared that people who had a great deal of contact with service providers, and who, for example lived in supported accommodation or attended day
centres, experienced transitions more smoothly, perhaps because things were more or less taken out of their hands, and the process was controlled elsewhere. For example, one user told us that his social worker would not let him leave hospital (allow the hospital to discharge him) until his alternative supported accommodation was set up, otherwise (he said) he would have been staying in bed and breakfast accommodation.

**Attitude and approach of user and provider**

Linked to the point made above, transitions appeared to be more smooth, and to lead to less discontinuity in provision, where either the user or the provider, or both, were pro-active in their approach to handling the transition. Where a service provider initiates contact with a known user who has moved home, this takes the burden off the user and ensures that they will continue to receive some level of service.

Where the user is pro-active, for example, in ringing up the relevant department and establishing their need for a service, then again this should mean that they are at least within the ‘system’ (although this is reliant on them being able to identify the relevant service).

However, respondents told us of the ‘downsides’ of being pro-active and a wariness about being ‘too pushy’. Partly, for some, it left them with a feeling of ‘begging’ for a service, and they found this demoralising. Others were anxious that by being over-pushy they might find themselves relegated to the bottom of a waiting list. Of course, not everyone has the ability or the inclination to chase services in this pro-active way. In particular, if the transition itself had led to a high level of anxiety and undermined confidence, then people did not feel able to take on this role.

Another disadvantage for the user of being ‘pushy’ is that their expectations of what they should get may clash with the assessment of the service provider, and this can obviously lead to tensions. There were some examples in this study where this appeared to have been the case - one woman who wanted to retain her independence and, therefore, resisted most help and support offered, but did request a downstairs shower, which she had not received.

**5.2.4 Summary of user perspective**

Moving house can lead to a number of changes in circumstances and need for services. The impacts on service delivery were varied, and the more negative impacts included delay in receiving services or loss of services altogether. Transitions made in relation to housing or home circumstances tended to be initiated by the user, but can be forced on someone, for example, if the supported accommodation they live in is closed down, or they are no longer able to cope in their current accommodation.

The evidence from users shows that making these kind of transitions can be confusing: where, for example, there was contact with a number professionals, or no clear communication about what was happening. Equally, users could feel as if
nothing was happening, if they experienced delays or lack of a new service or withdrawal of an existing one. Information, communication and co-ordination of service provision are important for the user. Where the user is not pro-active or ‘pushy’, and they have no member of family or independent ‘advocate’ to act on their behalf, then the transition is more likely to be a negative experience. Ideally, this pro-activity in managing the transition would come from a service provider rather than relying on there being someone who can initiate activity and follow-up delays.

Transitions across a local authority boundary can be especially fraught with difficulties. It appears to be unusual to be able to transfer a service across a boundary, and so users not only risk getting ‘lost’ if they do not, or cannot, establish new contacts in their new area, but they are very likely to lose their existing service package, and not necessarily have it replaced with a similar level or type of service. This tends to create a reluctance to move.

5.3 Service providers’ and policy officials’ views about enabling smooth transitions

Material in this section is drawn from interviews carried out among professionals from a number of different service areas:

- housing, including local authority housing departments, and voluntary sector housing services;
- social services, including professionals from local authority supported accommodation teams, community care teams, and a voluntary organisation running a Direct Payments scheme;
- health, including professionals from occupational therapy services; and
- joint teams, for example, professionals from a local Supporting People team (combining housing and social services staff), and from a learning disabilities team (combining health and social services staff).

The aim of the interviews was to investigate what professionals felt were the barriers to providing continuous provision when a user makes a transition, and what might be the ways of overcoming these barriers. In reporting their views, we have organised the material into two areas – organisational issues and budgetary issues. In Section 5.4, we go on to look at the role of national policy and initiatives in this area, and the extent to which service providers feel these initiatives can or do address some of the issues around continuity of service provision. Finally in Section 5.5 we provide an overview of this chapter and look at service providers’ views about where there are issues around the making of transitions that still need to be addressed. These last two sections draw on interviews with policy officials in the ODPM and DH as well as with local level service providers.
5.3.1 Organisational and procedural barriers and facilitators

There were a number of issues raised by service providers about how organisational structures and procedures could impact on the provision of services for smooth transitions. Some local authorities had set up mechanisms or procedures for addressing some of these issues, and these are discussed in the relevant sections below. The issues can be grouped into the following areas and are described in the sections that follow:

- lack of liaison and shared understanding between organisations offering different aspects of similar service;
- multiple assessments;
- isolation of the user from the decision-making process;
- lack of liaison between local authorities;
- organisational bureaucracy; and
- lack of knowledge among service providers of services in areas.

There were also some specific issues around housing adaptations and hospital discharge which are reported at the end of this section.

There was a strong feeling that despite a general intention of movement towards joint working, there still existed places where there was a lack of understanding and ongoing liaison between individual local provider departments or agencies across housing, social services and health sectors. Respondents felt that different service sectors operated within different organisational cultures, and that it was easy for there to be unreasonable expectations or inappropriate requests of a department when information and assumptions about service provision were not shared. The sort of language people used suggested the existence of a ‘them’ and ‘us’ culture in some areas, perhaps especially between health and social services. This was felt to be unhelpful to the user and might result in a service not being provided when it should be, or at the least a lack of clarity about the process of getting a service (as was echoed by findings from users in Section 5.2). These difficulties in creating closer working methods (see the examples) appeared to be more difficult where geographical boundaries did not match, so for example, within district councils versus county councils, or health authority areas versus social service areas. One local authority was changing its district boundaries in order to match the health boundaries.

Despite these ongoing difficulties with achieving closer working, there were plenty of individual examples from our respondents of ways of working that were attempting to overcome some of the more traditional boundaries and make service delivery more streamlined. The creation of multi-disciplinary teams in specific service areas (although not necessarily across the board) appeared to be a relatively common practice in our case study areas; for example, social service teams and health teams had formed a joint team to look at care provision for mental health service users, or users with learning disabilities. Similarly, there were examples
where housing and social services had arranged for occupational therapists from social services to be based within a housing team, in order to create a more unified delivery process (see below for details about Government guidelines on making housing adaptations).

These ways of working which were generally relatively new, were felt to be a positive development, particularly in terms of increasing levels of understanding between departments about their different roles and objectives, and the different ways of working within sectors:

‘You’ve got a much more informal sort of working relationship there at ground level that makes it so much easier to work together and to actually achieve things ….. You’ve got people who meet on a regular basis with each other, whereas before we would have these really focused meetings about an individual where you would have one side of the table arguing against the other whereas now it’s much broader and it has brought us all together and we do talk about more sort of strategic things and sort of philosophies and, you know, and how we want to deliver a service and I think that has probably broken down some of the barriers. It’s down to individuals, and I think as well the commitment from heads of departments.’

Service co-ordinator, Supporting People team, local authority

Multi-disciplinary teams were also felt to approach service needs with a focus on the user, rather than with an eye on organisational budgets or objectives. However, we do not have any evidence from users about how dealing with service providers with different sorts of internal structures might affect their experiences. There were also examples given which demonstrated the inevitable difficulty of creating structures across sectors which fully incorporated all perspectives: one authority had a joint health and social services learning disability team, but at the same time children with learning difficulties came under the responsibility of a separate children’s team within social services. The respondent felt that the learning disability team should provide a ‘cradle to grave’ service but was not able to do so because the children’s team were responsible for all children. People are likely to fall into more than one service provider ‘category’.

Setting up mechanisms for greater liaison between different local authority teams or sectors was another way of encouraging joint working and shared understandings, without changing the structure of specific teams. Examples of this included: a) regular mechanisms for sharing information (meetings, regular written updates etc.); b) creating a new ‘liaison’ post to deal with joint working issues; and c) creating joint working protocols between service areas (for example, housing and community psychiatric nursing) to set up a method of providing single person contact for the user (who would otherwise have to deal with both sets of professionals).

The issue of fixed ‘roles’ among professionals came up within different contexts. For people working as allied health professionals, this is due, in part, to regulations limiting their work to that within their ‘scope of practice’; however, there are
overlaps in the scope of practice, and it is down to local services to determine how to make use of different professional roles. Some respondents described local initiatives seeking to encourage greater role flexibility. For example, enabling social care staff to have the skills to carry out what were previously demarcated as ‘nursing’ tasks, and to do so in the home. The central role that GPs have in carrying out assessments was discussed, and (although user views suggest that users may welcome GP assessments) some professionals felt that GPs were not necessarily appropriately trained to carry out thorough assessments. Respondents also talked about the role of occupational therapists (OTs), and examples were given of reviewing not only which teams they should be part of, but also differentiating between situations where a qualified OT is clearly required, and situations where an assistant would be capable of carrying out an assessment themselves, therefore, making more efficient use of resources. The College of Occupational Therapists has been looking at the creation of a General OT practitioner, whose remit would encompass both health and social care responsibilities, including within integrated teams. They see this as ‘pivotal to an integrated approach that enables services to be developed as a continuum that is focused on, and responsive to, the needs of all service users and their carers’.

This issue of the most effective use of specialist skills is one we discuss in Chapter 6.

A related issue, and one which echoes our findings from users, was the way that **multiple assessments** carried out by different professionals could cause confusion and delays in transitions. This might involve more than one assessment for housing adaptations (by housing and by social services) or different assessments by health and social services for different aspects of services, e.g. ‘medically’-based versus ‘care’-based services (which may feel to the user to be an artificial distinction). Service provider staff were generally aware of this as a difficult issue in the overlap of provision between health, social services and housing. It was also noted that users with multiple impairments were likely to face the involvement of even greater numbers of professionals, given that they were likely to find themselves the focus of a number of different service teams (e.g. sensory and learning disability teams). The need for greater sharing of information about users between different service providers was recognised, but this clearly needs to be done within the boundaries of data protection procedures. It was felt that the introduction of ‘electronic patient records’ would help here. Also, some people in health and social services were already working towards carrying out single or joint assessments, in light of the Single Assessment Process initiative (see Section 5.4.4) and felt that this was a positive step forward.

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39 Allied Health Professionals are regulated by the Health Professional Council. There is the potential to work outside the scope of practice as long as this is supported by the clinical governance mechanism, which ensures that the individual has the relevant competencies and training for new ways of working.

One way that service providers had tried to deal with duplication of, and delays in, assessments, was carrying out an initial assessment by telephone. This was intended to act as a first level assessment, which could perhaps deal immediately with straightforward service needs, and filter other more complicated needs to the right person to carry out a more detailed and ‘holistic’ assessment. In this example, it was being tried by a social services team to assess how people manage their personal care at home, as a way of reducing their backlog, but it could presumably apply in other fields. Again, it remains to be seen how well this will work in practice from an organisational and user perspective.

One of the underlying objectives behind the move towards more joint working and smoother transitions, appears to be to create an environment in which the service user and their needs are the central focus of delivery. Our evidence from users shows that currently, this is clearly not always the case, and that users can still be isolated from the process, because it is shaped by organisational budgets and objectives. There were examples in our study of authorities who had sought to address this issue, and to create services where users were more involved and more in control of the process, being able to exercise choice over the service they were to use. Examples given were within the Direct Payments and Supporting People programmes, where people could select their choice of provider. One authority also talked about setting up a user-led lettings service for social housing, whereby users could browse an internet site and select the properties they preferred, rather than being allocated a property by housing services. It was argued that having the user more involved should lead to provision of more suitable services, but also should mean that the user was less likely to feel frustrated by the process, even if it did take a long time.

Respondents were asked about liaison between local authorities if a user was to move between different areas. Although examples were given of where occupational therapists from each authority had met up or held discussions to talk about the user’s needs for the transition, it appeared that this was more often the exception than the rule. Responsibility seemed to lie with the user themselves to initiate contact on moving to a new area, rather than on formal joint-working procedures between authorities. Where information was passed between local authorities, there were issues of data protection to consider, and procedures seemed to take a long time. Staff in one authority spoke about trying to help users to take equipment with them if they moved by giving them the opportunity to purchase the equipment, for example a hoist, at a reduced price (whereas the normal procedure would be to request it back). However, this raised the issue of responsibility for maintenance of the equipment, and whether the user would choose to take that on themselves or not.

Two final points in relation to difficulties hindering smooth transitions at an organisational level were a) the high level of time-consuming bureaucracy associated with some local authority departments and b) an incomplete map, or lack of awareness among service providers of all the local appropriate services which could lead to delays in identifying something suitable for the user. Some
authorities were carrying out exercises to map provision in different sectors in order to address this; and all authorities should have been doing so in the area of housing support services as part of the preparation for the Supporting People programme (see Section 5.4.3).

Housing adaptations

In addition to the range of factors discussed above, there were also some rather specific issues around housing adaptations. Firstly, people commented on how the adaptation process was, in some cases, an inevitably long one (even when it worked smoothly). This was, among other things, because of the need to identify suitable builders, to actually get the relevant work done, negotiate building and planning regulations, and obtain permission from private landlords where relevant. Good planning, co-ordination and communication with the user are, therefore, very important aspects of the adaptations process. In addition, it was argued that some of the rules of the Disabled Facilities Grant were restrictive in terms of helping people make housing adaptations, for example the rule requiring people to remain in a property for at least five years in order to qualify for major adaptations\(^{41}\), or the rule that the DFG could not be used to enable someone to move to a more suitable home, rather than getting adaptations made to their existing home. This latter rule has recently been changed so that DFG discretionary grants can be used to help with the costs of moving house.\(^ {42}\)

To help speed up adaptations processes, one authority had introduced a specific project whereby a dedicated person would visit people and carry out simple adaptations, such as installing stairlifts, within 24 hours of the assessment. There was a general feeling that social services and housing needed to work closely together on housing adaptations, and also that social services should be more involved generally at an early stage with housing placements, in order to prevent people moving into housing that subsequently proved to be unsuitable (or very expensive) to adapt.

Hospital discharge

There were also some more specific issues raised around the subject of hospital discharge. Respondents we spoke to were beginning to reflect the central Government drive towards improving hospital discharge procedures, in order to avoid ‘bed-blocking’ or re-admission, and exploring ways of more streamlined systems or closer working between health and social services. However, social services staff argued

\(^{41}\) ODPM suggest that the five year condition has little effect in practice: there is no clawback on the grant, and it would not affect future applications if someone was to move before the five year period was complete. In addition, the condition allows for someone to say they may have to move within five years if health or other relevant circumstances prevail.

\(^ {42}\) Regulatory Reform Order Housing Assistance, 2002.
that they were reliant on health professionals to involve them, and that health procedures could take a long time. Health workers made a similar point and argued that it could be quicker and easier to pay for the necessary care package or equipment on discharge out of their own budgets than wait to get funding approval from social services. OTs based in social services teams also described the practical difficulties involved in visiting and assessing patients who were perhaps based in a hospital in a different authority to their home. As with housing adaptations, co-ordination and long-term planning, ideally, well before the user is even admitted into hospital if it is a planned admission, were seen as the best way to address this issue.

5.3.2 Funding and budgetary barriers and facilitators
A number of issues arose specifically in relation to the level and structure of funding. While some of people’s concerns around funding inevitably focused directly or indirectly, on resource shortages, there were a number of other issues raised around the way funding was organised, or budgets were set up, that were felt to contribute to different degrees of discontinuity of service provision. The main types of issues can be grouped into the following categories, and are explored in turn below:

- resource shortages;
- budget boundaries;
- contracted-out services; and
- funding via a grant.

Service providers talked about insufficient levels of funding or resources in relation to a number of different impacts on service provision. In particular, people spoke about how lack of funding could result in longer delays in, for example, equipment or adaptations being provided. It was noted that this was particularly difficult towards the end of the financial year when budgets were more stretched. The budget for the DFG was felt to be too low to meet demand (in the areas where we carried out interviews), and, hence, resulted in waiting lists, for example of 18 months or longer: this was also said to be due to insufficient funding for grant administration. Central Government mandatory provision of the DFG currently operates with a ‘ceiling’ of £25,000 per person, and the onus is, therefore, on local authorities to allocate money from their capital expenditure budget to meet need for housing adaptations that goes over this. Some respondents felt that the £25,000 should be increased so that the local authority did not have to contribute as much themselves. Clearly, there is a national issue here in terms of the fixed ‘ceiling’ for DFG, but also a local issue in relation to how much local authorities choose to allocate from their own budgets. Where the DFG budget is relatively low, it was pointed out that it only takes a small number of major adaptations to use up a large proportion of the budget. Where the budget is limited, the judgement about what is ‘reasonable and practical’ to do in terms of adaptations is a hard decision to make. One service provider spoke about an option for home owners to release some equity
in their home in order to fund adaptations, but acknowledged that this is more difficult for people where their house is their only asset.

Resource shortages were also discussed in relation to staff shortages and insufficient levels of appropriate housing stock, for example, one area said they did not have enough supported accommodation for young disabled people, others said that their appropriate housing stock was unevenly distributed across the area, therefore, giving people limited choices about moving home. These issues vary by area depending on the nature of the housing stock and the needs of the local population. However, it was noted by another respondent that they felt there was a greater provision and choice about housing than there used to be, where local authorities were now working closely with housing associations and other providers (and, therefore, had access to place people in a range of different accommodation).

Staff shortages were noted particularly in the occupational therapy profession, but also more generally in the care sector. Staff shortages were said to result in a) delays in getting assessments or a service provided; and b) inability to be pro-active in relation to keeping in touch with or following up user needs. Shortages in staff were felt to come about, in part, due to the low status and low pay of these jobs, resulting in low recruitment levels, and poor job retention. The fact that training in occupational therapy was a long course, which often attracted limited funding, was also felt to be a disincentive.

Having limited budgets clearly points to the need to discriminate within a service between areas that can and areas that cannot, be funded. The result of this is prioritisation of needs, and the creation of eligibility criteria to determine need thresholds. These boundaries were sometimes seen by staff or users as unfair and somewhat arbitrary, for example that a provider is not allowed to provide a housework service to users unless they are assessed as having personal care needs. It results in the use of **budget boundaries** around what can and cannot, be funded out of the budget. There are two aspects of budget boundaries: service provision that falls outside a budget responsibility (and is not necessarily picked up elsewhere), and service provision that is ‘shared’ between more than one sector, for example, housing adaptations being shared between social services and housing (see below). Budget boundaries are, therefore, partly the result of limited budgets and necessary decisions about what is reasonable to provide. They are also underpinned by the way that legislation is framed and has developed over the years, for example, that social services are not legally able to take full responsibility for housing adaptations.

Service provider staff were also aware that the overall pot of money was limited and this meant that they were ‘in competition’ with other teams or departments for funding – one respondent commented that the removal of a ring-fenced budget for the learning disabilities team resulted in the budget getting lower (although there could be the opposite effect).

Budget boundaries were also said to cause a range of difficulties in relation to providing continuity of service for a user – either because the service user’s needs
could not be met out of the particular budget, or because there would need to be liaison with, and between, different departments in order for different types of need to be met. This included, for example, the provision of different types of equipment, and different types of home care and support divided between social services and health providers. Making adaptations to housing was a key area where the division of budget and assessment responsibilities between housing and social services departments, was said to lead to difficulties in providing a smooth service for the user (housing adaptations are discussed in more detail below). Some local authorities had set up ways of working to overcome some of these budget boundaries, these included:

- delegating decisions about budget spending on housing adaptations from housing to social services;
- enabling health professionals to authorise the purchase of equipment up to the value of £250, thereby speeding up the process of, for example, hospital discharge if only minor equipment is required;
- training social services care staff to carry out medical/nursing functions (see below for more detail); and
- joint funding of equipment or care packages by health and social services: although the benefits of joint funding in terms of smoother provision and closer liaison were noted, it was also commented that it raises a number of issues, for example if equipment is purchased jointly who owns it and who maintains it? Further, if either of the health or social services teams have a more generous budget than the other, then seeking to have both teams involved in providing funding could potentially cause a delay for the user.

The Integrating Community Equipment services initiative (see below) aims to address some of these issues.

An organisation or agency providing services to the local authority under contract, for example, a Direct Payments service, can find themselves in a slightly vulnerable position financially in terms of budget planning. One provider we spoke to said that they were unsure how they would cope with funding the service if they ended up getting more referrals than they had been contracted to deal with. There was a nervousness about returning to negotiate contract conditions with the local authority in case they were to lose the contract: this was the provider’s first experience of providing this service for the local authority.

Finally, it was the view of one respondent that funding of a service via a grant, for example, the Disabled Facilities Grant or the Independent Living Fund, inevitably involved more time and lengthy procedures than something that was funded directly by the local authority, because of the need for individuals to make an application and be assessed. The Disabled Facilities Grant, in particular, was felt to be a slow process, and the rules fairly rigid compared to funding for housing adaptations directly from the social services budget (which would happen for public sector housing):
'I think we have a fair amount of flexibility possibly, within Social Services, but... the rulings regarding the disabled facilities grants that they are possibly more rigid... Well, building control, the grant, the whole thing is a slow process, ...you've got to start off with assessment from us, there's the Environmental Health Department, you've got - clients often use an agency, a housing agency for the technical support and to act on their behalf because it's a complicated process, and the grant application to be completed and approved, drawings to get right, out to tender, three quotes, building regs or whatever you need for that particular scheme. Then the quote, then the pre-start meeting, then the job, it's a long process.'

Practice manager, physical disabilities team, local social services department

5.4 Recent developments in national policy and initiatives

In this section we look at the role of national policy and national initiatives in hindering or facilitating smooth transitions. This draws on the views of both local service providers and central Government policy officials. We will look in turn at a number of different initiatives and describe how they seek to address the issues identified.

5.4.1 New guidelines for delivering housing adaptations

This is a joint document, drawn up by the Office of the Deputy Prime Minister (ODPM) and the Department of Health (DH) that is intended to be published in spring 2004. The document was drawn up with the intention of addressing the difficulties faced in making housing adaptations, namely delays for the user, lack of joint working between different local authority departments, and the existence of a number of different legislative areas that govern housing adaptations. Guidance under this document is not made under statutory powers, rather it is recommending best practice to local authorities, providing examples of effective ways of working. The guidance recommends that there should be a unified team, comprising occupational therapists and housing officials, who agree the way forward for housing adaptations. This should avoid disagreements or difficulties due to misunderstanding between departments. It is also suggested that the role of occupational therapy assistants could be enhanced for assessing minor adaptations, for initial screening and for progress chasing (within a framework of good support and supervision). Guidance is also given on waiting times, that no-one should have to wait longer than a year for an adaptation; this should help to address the question of delays, although not if the delays are due to inadequate funds set aside for adaptations budgets. Local authorities will obviously need to allocate money themselves initially to help establish new best practice systems, although whether these systems will save money or cost more in the long run is not known.

In addition, from June 2003, councils may not charge recipients (under community care regulations) of minor adaptations (i.e. those under £1,000). By December 2004, minor adaptations should be completed within 7 days.

A further change has been made to the Disabled Facilities Grant, which addresses one of the issues raised in our research by service providers in relation to inflexibility. New regulatory powers have made it possible for a local authority to make a discretionary grant for moving house, which could be offered instead of a grant to adapt an existing home. It could be that the costs of moving home will mean that such an option would tend to be very expensive and, therefore, not used very often. Some authorities have said they will offer this, but with a ceiling of £25,000.

5.4.2 Role of Home Improvement Agencies

Home Improvement Agencies (HIAs) are organisations that provide a co-ordinating and liaison role on behalf of the service user during a housing adaptations process. They should, therefore, help the user through a transition, in particular reducing confusion and delays. Although they have been in operation since the late 1980s, they have not always been very well funded, and the way they operate and the size of their operation has varied hugely across the country. As a result of a recent review, HIAs have been seen as providing a key role in helping to focus on user needs (rather than competing department objectives) and providing the user with a central contact point and someone who can ‘chase’ things on their behalf. Their ability to co-ordinate and foster relationships with builders and other contractors is also felt to aid the adaptations process. Given this, the ODPM is now aiming to increase the size and coverage of HIAs so they can be used as a more standard delivery mechanism. Their role and structure in relation to the local authority housing department is likely to vary, some HIAs may deliver the Disabled Facilities Grant and some may just co-ordinate the process. It will be interesting to see how these changes affect user experience of the housing adaptations process.

In addition, the Department of Health is now putting funding into HIAs under the hospital discharge schemes, in recognition of the need for planning and co-ordination of adaptations, to aid a quick and smooth discharge from hospital. This is a good example of joint working between departments, recognising the need for a single delivery mechanism to meet different departmental objectives.

5.4.3 Supporting People programme

Supporting People is a new programme, operating out of the Office of the Deputy Prime Minister, and working closely alongside the Department of Health. Its overall aim is to help vulnerable people maintain independent living in their home, through provision of ‘housing support’ services (differentiated from ‘personal care’ services). It is, therefore, aimed at addressing the issue of avoiding unnecessary transitions, but also making sure people receive appropriate services on making a transition. One of the motivations for setting up Supporting People was a recognition that housing support services were suffering from a lack of co-ordination and
strategic approach – there was a range of different funding streams, and potential for gaps and duplication as a result. The early phases of Supporting People, therefore, involved a national mapping exercise, to identify relevant services and measure demand for those services.

Since April 2003, Supporting People has been delivered through a locally-based Supporting People team who administer funding and carry out service reviews for a wide range of service providers operating under contract. The overall programme within each local authority area is run by a local commissioning body, which should include representatives from the local authority (including both district and county councils, in the case of two-tier administrations), the Primary Care Trust, and the local probation services. The hope of the programme designers is that representatives will all have a stake in the operation of Supporting People because of the transfer of funds from their own areas of responsibility, and that, by bringing them together to reach joint objectives and priorities, they will act in a co-ordinated and strategic way to meet individual user needs. It is also hoped that the existence of this body will focus attention more on monitoring the quality of services and looking at value for money. Greater knowledge of available local services, should also help to meet user needs more appropriately and more speedily.

5.4.4 Single Assessment Process

The Single Assessment Process is a programme initiated by the Department of Health. It currently applies to older people’s services only, and was initiated as part of the National Service Framework for Older People. Local NHS bodies and Councils began implementing it from April 2003. Its purpose is to ‘promote better care services and better outcomes for older people, and more effective use of professional resources’. Part of this aim is to avoid duplication of assessments. It applies specifically to health and social care, but local agencies are expected to include all relevant service providers, including for example, housing, transport or finance services. The intention is that local agencies will develop a common approach to assessment and joint working arrangements at a local level.

5.4.5 Integrating Community Equipment Services initiative

The provision of equipment separately by health and social services has been recognised as being a key barrier to enabling transitions out of hospital, as well as delaying the delivery of equipment to people with changing needs who are living at home. The aim of the Integrating Community Equipment Services (ICES) initiative, run within the Department of Health, is to bring agencies together in the delivery of equipment by pooling equipment stocks and budgets. The initiative operates under the 1999 Health Act, and is intended to reach the NHS Plan targets by April 2004. Section 31 of the Health Act enables partnership arrangements for pooled budgets and lead partners for integrated services. ICES aims to address issues of delays as well as helping people to receive the equipment they need. As well as health and social services agencies, this will include working closely with housing, education, employment and voluntary sectors. The targets of this initiative are to
increase the number of equipment users by 50% and provide equipment within seven days of assessment.

Under this initiative, the DH is also looking at a number of other issues and exploring possible solutions. For example, they are exploring options for self-assessment in supermarkets or mobile libraries to aid rapid access to equipment; and investigating the idea of a children’s equipment library whereby families could swap equipment, given the rapidly changing needs of children.

5.4.6 Direct Payments

Direct Payments is a scheme run by the Department of Health which has been in operation since 1996, and in April 2003, it was made obligatory for local authorities to offer it to eligible disabled adults (16+) or parents of disabled children. Its main objective is to enhance user choice and control over services, and in this way, it has the potential to address some of the difficulties described by users in relation to delays or discontinuity of service on making a transition, because the user remains in control of the service throughout the transition. It is an alternative way of offering services to people to help promote independent living, whereby users are given cash payments to use to employ someone to provide services. Examples of ways that Direct Payments could aid a transition include being able to employ a personal assistant to help with making a transition into work, or in funding activities to learn about independent living prior to moving away from a residential care setting.

However, local service providers pointed out that it is also subject as a scheme, to some of the same difficulties in delivery as other social services, for example, delays in getting an initial social services assessment (in order to access a direct payments scheme), and variability in level of service between different local authority areas. There are also some specific issues around Direct Payments, the most common concern voiced by some local authorities being the issues that arise for users in becoming employers and dealing with that responsibility. As a result, some authorities are reluctant to offer Direct Payments, especially for certain groups, for example, older people, or people with mental health problems or learning difficulties.

5.5 Chapter overview

In reviewing the evidence from the two main groups of respondents, service users and service providers, two main ‘problems’ emerge as key for the user when they make a transition in the area of housing or support at home. These are:

- experiencing delays in receiving services following their transition; and

- not receiving the service they need (either because they lose a service they did have, or do not receive a service they now need, or do receive a service but they consider it to be inadequate or inappropriate).
A third problem for users is finding the transition process, including trying to get appropriate services, stressful and confusing. There are two main problems that underpin this: first, lack of awareness among service users about existing services, hindering a user from knowing what they can receive or apply for; and second, lack of choice and control by the user over the process. More involvement may help users to withstand a delay better, but also helps to ensure that they feel that the service they receive is appropriate in meeting their needs.

In this section, we pull together the findings displayed in the chapter, and look at the following areas:

- the range of barriers that make it difficult for service providers to provide a smooth transition;
- the origins of these barriers; and
- examples of national initiatives or local practice that attempt to address these problems.

The issues to be considered for policy development are brought together in Section 5.5.2.

5.5.1 Summary of barriers

The barriers summarised here have been divided into whether they are organisational, procedural or budgetary barriers. However, there are clearly overlaps between these different types of barriers, as is made clear within each sub-section.

Organisational barriers

The division of a service between sectors, for example housing adaptations provided by both housing and social services, or care services being provided by both health and social services has led to the risk of a number of impacts for a service user as described in this chapter, including delays in receiving a service or perhaps not getting a service at all, because of the need for liaison between organisations. One example of a barrier to creating more integrated services is that different sectors have different financing systems, which may make it difficult to co-ordinate delivery on the ground.

At the same time, the structure and organisation of service providers at a local level meant that provision for any individual service user was often split between different organisations or teams within an organisation. Insufficient sharing of information, different organisational aims and objectives, and lack of co-ordination of the service delivery process can all cause delays or discontinuity for service users. Lack of procedures to manage the assessment process (so that information is shared, or a single person carries out the assessment, or the need for more than one assessment is co-ordinated as a process) appear to be a particularly difficult aspect for the user. This is clearly a central as well as a local issue, in terms of recommending or determining appropriate areas of responsibility.
The autonomy granted to local authorities to shape their own service delivery structures or budget allocations and eligibility decisions can lead to differences in receipt of service following a move across a local authority boundary. The lack of established links between local authorities causes difficulties for service users making a transition across local authority boundaries, for example, not being able to transfer equipment from one authority to another. The roots of this barrier lie partly in the lack of flexibility around budget accountability within individual local authorities, and also with differences in the organisation and provision of services.

The role of professional staff was central in shaping people’s experiences of transition. There was said to be a national shortage of staff in the care sector generally, causing staff to have heavy workloads and, therefore, not always be able to deal appropriately or pro-actively with service user needs. This was linked to a perception that professional areas of responsibility were perhaps too fixed, and a suggestion that the introduction of a more flexible approach (perhaps via professional bodies) towards who was able to carry out assessments, or other aspects of service delivery, would lead to fewer delays and discontinuities for the service user.

### Procedural barriers

Eligibility for the receipt of some services is determined by national criteria, for example, the Disabled Facilities Grant. With rules of eligibility, some people are inevitably ruled out from receiving a service they feel they are entitled to, or are only eligible to receive it if they make a financial contribution. They may, therefore, lose a service they feel they need following a transition. This is also a local issue when it comes to the local interpretation or setting of eligibility rules.

There are a number of central regulations around getting building works done for housing adaptations which cause the process to be a lengthy one. Getting planning permission, ensuring minimum standards for health and safety in building all take time. There were no clear suggestions from the research about where these regulations or procedures could be improved to help transitions.

A low level of awareness of existing services among local service providers was said to sometimes cause barriers for users to access a suitable service quickly or at all. Better procedures are needed for recording information about relevant services, and liaison between services in order to understand the nature of the service.

### Budgetary barriers

Delays in receiving services were said to be a result of limited availability of resources such as appropriate housing stock. This is a local issue as well as a national issue in terms of the building of new homes and allocation of existing properties.

There was a suggestion that individual staff workloads at a local level (for example among occupational therapists) were such that it was difficult for staff to manage the transition process for service users in the way they would like to do. This may be a budgetary issue, or it may suggest the need for caseload management or other staff training issues.
Initiatives to address barriers

- The need for better ‘joint working’ between the health, housing and social services sectors is well-recognised, and a number of initiatives have been set up that seek to address some of the issues: the Single Assessment Process, the Integrating Community Equipment Services initiative, Home Improvement Agencies, the Supporting People Programme, and the ODPM/DH guidelines on making housing adaptations. They are all relatively new, and it is, therefore, too early to tell what impact they may have.

- Locally too, there are examples from the research of joint working between these three sectors, in the setting up of multi-disciplinary teams, or the creation of specific procedures aimed at producing closer liaison (see Section 5.3.1).

- A few initiatives are seeking to address the issue of continuity of service across local authority boundaries. The DH’s Fair Access to Care Services guidance, advises that levels of service on offer should be similar for anyone with similar levels of need; and the Supporting People programme is setting up Cross-Authority Groups with a view to looking at transitions between neighbouring local authorities. At a local level, some local authorities offer users the opportunity to purchase their equipment at a discounted rate so that they can take it with them. It still appears that the primary responsibility lies with the user to contact service providers in a new area, or to challenge service providers who provide a different level of service.

- The Single Assessment Process initiative is beginning to look at how the problem of multiple assessments might be addressed. However, it is still very new, and does not incorporate assessments in some areas, for example, housing support, and currently only applies in the area of older people’s services.

- There were examples in the research of where local service providers had set out to speed up processes without increasing spending. These basically involved reviewing a service and identifying whether there were aspects of it that could be delivered more quickly via a separate mechanism – a sort of ‘two-tier’ system. For example, straightforward assessments carried out by telephone, or quick and easy adaptations carried out on a more ‘quick response’ basis via a dedicated member of staff.

5.5.2 Issues to consider for policy development

- **Raising levels of awareness among service providers and users**: this would enable both users and service providers to be more pro-active in finding an appropriate service following a transition. It is important that this is done for service providers in a systematic way (e.g. recorded and updated, perhaps via a database form) rather than reliant on word of mouth and the specialist acquired knowledge of individuals. Action could be at a national and a local level, depending on how locally based the service is. However, it may result in increased demand for services and therefore requiring an increased budget to meet this demand.
• **Increasing user choice and control**: as with the previous point, enhanced user choice and control would help match need to the service provided. It may also smooth the transition process, or at least reduce levels of frustration. However, from a service provider point of view it may lead to mismatch of what they feel able to provide compared to what the service user wishes. Also, from a user point of view, the amount and type of choice and control needs to be in line with what they feel they can manage, and with support if appropriate. This is clearly both a national policy issue in terms of the overall design of programmes, but also a local issue in terms of the way programmes are implemented.

• **Closer joint working between social services, health and housing**: there is a need for ongoing reviews of organisational structures and procedures in order to address issues of insufficient sharing of information, mismatch of objectives, and lack of co-ordination of the transition process for the user. There may also be a need to review divisions of responsibility for different service provision between sectors, some of which may involve legislative review. However, this is a complex area, which needs careful consideration (and evaluation) within individual organisations to make sure it is not introducing further barriers. It is worth bearing in mind that the creation of multi-disciplinary teams may still not address gaps in service provision for all users, because people do not fall neatly into one official ‘category’ or another. Another option is consider setting up ‘co-ordinating’ agencies to oversee the transition (in the way that Home Improvement Agencies can do). It is also important to recognise that establishing joint working may involve costs to an organisation.

• **Closer joint working across local authorities**: there is scope to explore innovative mechanisms for joint working between local authorities in order to address lack of shared information, keeping track of a service user who moves, and continuity of service and equipment provision. It may be necessary to look at how data protection issues impact on the sharing of information about service users.

• **Greater streamlining of assessments**: there is continued need to reduce the number of assessments people undergo, by moving towards more joint assessments and sharing of information. However it is also important not to dilute specialist assessment knowledge (e.g. impairment- or service-specific knowledge). It is also important that assessments avoid becoming too simplistic and, therefore, overlook the full range of issues, including personal or family issues where relevant. It could be that more work is needed to look at what flexibility can be introduced into professional roles without jeopardising quality control (for example, more junior staff making assessments, with support, for minor adaptations, or referrals being made without the need for a GP as intermediary). Some of the entrenched ways of working around different professional roles may take some time to break down and they clearly need to be part of an ongoing debate and discussion involving a wide range of stakeholders.
Establishing appropriate level of checks and balances: checks on the decisions of staff delivering services are essential for ensuring quality control and accountability. However, there may be scope for reviewing these procedures to make sure there is a minimum threshold but no unnecessary bureaucracy. The appropriate level and procedure for decision-making is likely to vary between organisations and sectors, and depend on the nature of the service involved.
6 Barriers to smooth transitions and issues for policy development: an overview

6.1 Introduction

This chapter draws on the interviews with service users, providers and policy specialists across all transition types and presents an overview of:

- the difficulties that disabled people face when making a transition;
- the barriers to smooth transitions and their roots;
- what is being done to address the barriers; and
- what still needs to be done to address the remaining barriers in terms of areas for policy development.

6.2 Difficulties faced by disabled people making a transition

A review of the data revealed two main difficulties faced by disabled people making a transition:

- not getting the service they need (including a new need not being met or losing an existing service). Examples included:
  - a child moving to a new school losing on-site provision of specialist equipment or therapies; and
  - losing home care service as a result of moving across a local authority boundary;
• delays in getting the service they need. Examples included:
  - structural changes to a primary school not being ready in time for the start of term thus delaying the transition from nursery to infant school;
  - not having the IT equipment in place to start a new job; and
  - adaptations not ready in time for the move to a new home.

Alongside the concerns about the potential difficulties noted, some disabled people also had to cope with the stress caused by not being adequately informed by service providers prior to the transition. There was a lack of information and guidance from service providers about what is available, service eligibility criteria, and the possible impact of making a transition on current and future service provision. These led to numerous questions from disabled people such as: ‘Will the bus still take me to college once I’ve transferred to adult services?’, ‘Will my employer be able to meet the changing needs of my impairment?’, and ‘Will my new local authority allow me to keep my package of care?’ In other words, the lack of information offered by service providers about the process and consequences of making a transition could make it a very uncertain period in a disabled person’s life.

6.3 Barriers to smooth transitions

Before examining the barriers to smooth transitions and their origins, it is useful to consider the political context within which services operate. The last ten to fifteen years have seen significant movement in wider policy that has influenced the ethos of both service design and service delivery. Among the re-considerations in service design has been the shift from notions of ‘special needs’, and ‘separate provision’ towards ideas such as ‘inclusiveness’ and ‘integration’; the move from institutional care to community care; and the swing from resource-led to user-led services. In terms of service delivery, the impact has been evident in changes including the emergence of new service providers (such as contracted services provided by private and voluntary sectors), and the increasing devolution of budgets and management (for example, to Health Care Trusts and the creation of the Welsh Assembly and the Scottish Executive). It is within this context, therefore, that we should discuss the barriers to smooth transitions. The barriers can be divided into the following areas:

• structural issues;
• procedural issues; and
• budgetary issues.

The categories used to explain the origins of these barriers were introduced in Section 1.5.2). It was noted that for some barriers it was clear that they were centrally driven (i.e. by central Government legislation and policy design). However, the origin of others was not so clear. These appeared to be the result of both central policy and local implementation (and are described as central and/or locally driven barriers).
6.3.1 Centrally-driven barriers

The statutory services that this study considered operate within a policy and legislative framework. Certain aspects of that framework created barriers that meant that disabled people did not receive a service that they needed or received it with delays. It is important to make clear at the outset that these points are based on the perceptions of the service providers. In other words it may be the case that they are operating under the misapprehension that the way that their services are organised and delivered is controlled centrally (i.e. through policy and legislation), whereas in reality this has been determined locally. In spite of this, in terms of the end result – i.e. a disabled person making a transition experiencing delays in receiving a service or not receiving a service at all – the points are just as fundamental. The difficulties perceived to be created by legislation and policy are discussed under the following headings:

- structural barriers;
- procedural barriers; and
- budgetary barriers.

Structural barriers

The implementation of a policy may specify the format of the structure that the service delivery organisation adopts. On occasions the proposed structure could bring with it unhelpful consequences. For example, not being in the ‘right’ part of an organisational structure can create barriers to service delivery. It can mean that the service is not in a position to influence decision making or take part in information exchange. One example of this was Access to Work, which operates from regional administrative bases rather than at a more local level. This geographical location means that it is not coterminous with social services disability teams, nor located alongside Jobcentre Plus administrative bases and this can leave it outside the information ‘loop’. Another example is transport services which can also be outside the ‘loop’ because they are based in the section of the council that deals with roads, pavements and potholes, so they can be excluded from disability-related forums. This could lead to a lack of profile of these services among other providers and affect timely referrals.

Procedural barriers

Government legislation and policy were usually accompanied by centrally-designed procedures to facilitate their implementation. In some cases, these procedures were seen as being unhelpful to service delivery and, thus, to smooth transitions.

One instance cited was Access to Work’s funding procedures which could have negative consequences for the ease with which a disabled person making a transition could transfer equipment. For example, an individual making a transition from education to employment who needs to take a piece of equipment purchased by the Learning and Skills Council with them, may find that the college is happy for
them to take the equipment with them, but not until the local Learning and Skills Council has been reimbursed by Access to Work. This could mean that the disabled person has to start their new job without the appropriate equipment.

There were also cases where a procedure may have been designed specifically to reduce barriers, but in practice, did not always do so. An example of this is the UCAS application form which requests the indication of disability status from prospective students. This should enable planning of services prior to the student’s arrival. However, because it is a centralised procedure and that information is part of the form which is seen by those assessing applications, there can be a reluctance for disabled students to disclose such details, and hence, the opportunity to make a smooth transition can be missed.

**Budgetary barriers**

Centrally determined **funding structures** could also create barriers to smooth transitions. An example of how funding structures can affect service delivery is evident in the consequences of the differing funding structures operating within FE and HE. The shift to having to apply for funds on an individual basis for HE, which is not the case in FE, could lead to complications and delays for students making a transition from FE to HE who were not aware (or not made aware) of the differences in funding structures. For those colleges running both FE and HE courses and, consequently, operating both funding structures, it also created the administrative complication of having to deal differently with two students with the same needs. In Scotland, these issues are being addressed through proposals for the FE and HE funding councils to be merged, with the intention of creating a more integrated approach to the whole FE/HE spectrum and funding system.

Although we did not set out in the research to focus on issues around resource shortages, it was a recurring theme among respondents. In other words **insufficient funding** or resources to meet demand was identified as a barrier to ensuring that services were delivered and delivered on time. An example given here was the budget allocation to the Disabled Facilities Grant, which was considered to be inadequate to meet demand.

### 6.3.2 Central and/or locally-driven barriers

The research also identified other barriers where the root of the cause was not so clear. These barriers could have been created by the policy design or by the way in which the service was delivered, or indeed by both. These are also examined under the following headings:

- structural barriers;
- procedural barriers; and
- budgetary barriers.
Structural barriers

Organisations attempt to structure themselves in a way that enables them to meet the needs of their users. However, sometimes the way that a service is structured can create barriers to potential and current service users accessing and using services.

The sheer amount of legislation and policy designed to deliver services to disabled people is reflected in the large number of providers operating to deliver these services; in itself, this would seem to make co-ordination between, and access to, these organisations difficult. However, on closer inspection, it is not just a matter of the number of service providers but the fact that due to policy design (which usually means that different services are financed from different budgets), they are located within various sectors, which can also contribute to co-ordination difficulties. An illustration of this point involves the range of services dealing with children and young people, including LEAs (e.g. mainstream and special schools), health (e.g. speech therapy, physiotherapy), and local authorities (e.g. transport from a private service provider contracted by the education department). These have very different structures which inevitably bring with them a range of procedures, funding and ‘culture and ethos’ which could be a challenge for an individual who requires services from them all.

A related point involves the structuring of local authorities. Legislation has enabled local authorities to exercise a degree of autonomy in determining their service delivery structures or budget allocations and eligibility decisions. Whilst this allows flexibility and control, it can also lead to differences in receipt of service following a move across a local authority boundary, which may go some way to explaining why such a transition appeared to be especially difficult to complete smoothly.

There appears to be an ongoing debate about whether services for disabled people should be structured along specialist or generalist lines, and which one is more likely to facilitate a transition by creating fewer barriers. One pro-specialist argument was that this would produce a more focused, knowledgeable and expert service. An example involved having a disabled person’s housing service as opposed to a general housing service which meant that it was a more focused and specialised service that could work more flexibly. However, such an approach in some cases led to the involvement of fewer professionals and, therefore, reduced the need for liaison and co-ordination, which could hamper awareness among professionals of each other’s roles. It could also limit the number of points of access for service users. All of these points could be less than conducive to an efficient service delivery. A generalist approach also brought with it a range of possible barriers including the potential increase in access points for service users that could produce a lack of focus and ownership leading to delays and disruption in services.

There was also a wider debate about the value of multi-disciplinary teams (e.g. health and social services professionals in the same team) and whether this was more likely to lead to smoother transitions. Although they would be multi-disciplinary teams they would nonetheless be specialist teams demarcating along
one line or another, e.g. learning disability or mental health or children teams. A multi-disciplinary team, for example, comprising health and social services professionals providing a service for people with learning disabilities, would necessitate joint working between those two sets of professionals. However, it may simply re-arrange boundaries along different lines, where each multi-disciplinary team develops its own procedures, practices and ‘culture’ and problems such as lack of awareness of each other’s roles and remits, and, therefore, lack of referral and signposting continue.

Procedural barriers

In order to meet their aims and objectives, it was usual for service providers to design their own sets of procedural guidelines. However, even providers within the same service area had different aims and objectives, which could, on occasions, create conflicting procedural guidelines. One way in which this incompatibility showed itself was with some disabled people not receiving a service or receiving it but with delays.

There are broadly three stages in the process of becoming a service user – accessing/being referred to services, being assessed for services, and actually using services – and each entails its own set of procedures that can create barriers. In addition, there are also consequences of not following procedures or indeed not having procedures to follow.

- **Procedures for accessing service**: the first, and perhaps obvious, point to note is that to be able to access a service requires awareness, on the part of the potential service user or the service providers, of the existence of the service required. This was not always the case. Where the service provider was not aware of certain services they were then not able to make a referral and this then created the first barrier. Presuming that a referral was made or a disabled person self-referred, not following the correct procedures for accessing services (again, usually because of lack of awareness) could lead to delays in receiving services, and, hence, the second barrier. For example, it is the employee (or someone on their behalf) who should make the application to Access to Work, and not the employer. However, if the employer mistakenly approaches Access to Work, the application may have to be resubmitted and, thus, cause delays. This highlights issues of information and awareness raising.

- **Procedures for being assessed for services**: in terms of procedures, one of the key areas concerns assessments for determining eligibility for services. It should be noted that a lot of work has already taken place in this area including the Assessment Planning Implementation Review (APIR) and the Single Assessment Process. Equally important to note, however, is that both are only applicable to specific age groups. These are relatively recent developments and their impact cannot yet be evaluated. Nevertheless, there was evidence that concerns about the assessment process continue. These included: duplication of assessments; not involving all the appropriate professionals; and not having all the information necessary for an assessment, all of which can create barriers to a smooth transition:
- There are situations where the procedures that are followed are shaped by both legislation and by local practices that have grown over many years, and pinpointing exactly what created the barrier becomes difficult. An example of this is the issue of duplication of assessments within the same organisation and between organisations. An illustration of the latter involved social services and health services, where despite having identified a need, health professionals were required to refer to social services for an assessment to meet that need. This may be due to the lack of professional trust in each other or to the issue of liability framed by legislation, for example, if health services had ordered a piece of social services equipment, and there is a problem, who then is liable? Whatever the reason, the end result for a disabled person could involve delays in receiving a service. However, this is not to say that there is not a place for repeating assessments. Indeed, certain services, such as eyesight-related services, would not suggest that only one eye test was carried out and never repeated throughout an individual’s lifetime.

- An illustration of not involving all the correct personnel was found in schools where, for example, speech and communication therapists were not invited to the assessments. There was a general feeling that the appropriate professionals were not being invited because of the lack of understanding about each other’s roles. The danger of not involving the correct personnel was pointed out by one service provider who commented ‘How can someone with a degree in social work be making decisions about how much physio someone needs or what their speech and communication needs are?’ Related to this was the inadequacy of assessment in terms of the involvement of contracted services; most commonly in our sample this was transport services. Due to their contracted status they had a slightly different relationship to statutory service providers. They were usually not part of the assessment process and relied on social workers to cover transport issues, which, in their opinion, was sometimes not adequately done and resulted in inappropriate services being delivered. From the point of view of the disabled person this could result in them not receiving an appropriate service, experiencing delays in receiving services, or even not receiving a service at all. The need to have the correct personnel involved in the assessment process also raises the issue of need for a high degree of co-ordination.

- Not having all the information needed for an assessment was another potential barrier to a smooth transition. This was especially the case when a transition involved moving across a local authority boundary because more than one service was often affected. There was a need for full and timely sharing of information about the user among the professionals to enable transition planning. However, there was evidence of this not always being the case. There appeared to be a reluctance to share information about the disabled person (this could be due to conflicting procedural guidelines that made sharing information difficult or ‘professional territorialism’ that created a climate not conducive to collaboration), which could delay the transition.
Procedures involved whilst using services: once a person has accessed and is assessed to be eligible for a service there are still procedures that can hinder the transition. An example involves transport services contracted to a local authority education department. For example, if parents wanted their child to be picked up at a new location they tended to inform the transport service (e.g. the driver of the minibus). However, the education department is the customer of the contracted service and the parents are required to inform the department of any changes. The transport service does not have the authority to take that decision.

Finally, there are the consequences to consider of not following procedures or not having any procedures to follow.

- Procedures are not always followed, especially in emergencies. A point in case involves making a transition across local authority boundary for a school. Here, it is the responsibility of the placing local authority to check that the ‘new’ local authority has the provision needed, e.g. an appropriate school for emotionally disturbed children, but there is not always sufficient time to do this if it is an emergency placement. Then the new local authority has the obligation to try and meet the requirements of the child’s statement even if the local authority do not have the appropriate resource. It may have to use independent or non-local authority maintained schools alongside high cost teaching support. Another case where procedures do not always appear to be followed involves the variation among LEAs in the interpretation of the DSA eligibility criteria. For example, some LEAs had ‘capped’ resources which students with particular types of disabilities could claim, which goes directly against DfES guidance and makes it difficult for people to be able to predict what they will be entitled to if they move into education.

- The very lack of procedures could also cause delays and act as a barrier to a smooth transition. There was a general feeling that as services grew and became more complex there was a need to document procedures. The lack of formal procedures could mean that staff, and maybe more importantly, new staff, were not aware of what is available, or who does what. This could mean that what a disabled person receives very much depends on the worker they see and that worker’s level of awareness of services, which returns to the issue of the difficulty for some service providers in making referrals. There could also be lack of procedures in terms of collecting management information. The lack of such data could hinder the informed prediction of future service needs on many levels (nationally, at local authority and health trust level, for schools) and make it difficult to plan for smooth transitions (for example, schools may not have sufficient capacity to accommodate children due to under-estimating the number of required places and adult services having to respond to a child entering adult services as a ‘crisis’ because of lack of forewarning).

Budgetary barriers

Not withstanding the pivotal role that budget levels played in shaping service delivery (for example in terms of staffing shortages, such as the shortages in
occupational therapists which meant that there were delays in carrying out
assessments for people applying for the Disabled Facilities Grant), the ways in which
those budgets were organised could also have wide ranging consequences. They
could influence the provider’s capacity to make, receive or respond to referrals, all of
which could cause delays in a disabled person receiving a service.

- **Consequences of end of financial year**: some services that managed their
  budgets on a yearly cycle found that the point in the financial year at which the
  service needs of a transition arose, appeared to influence their ability to meet
  that need. In some instances, a shortfall in resources experienced by one service
  provider could have an impact on another. For example, a social services
  department reported having to delay meeting requests near the end of the
  financial year such as providing equipment to enable a discharge home from
  hospital. In this case, the resulting longer stays in hospital had consequences for
  health services.

  The experience of end of financial year did not affect all service providers in the
  same way. For example, Access to Work appeared to have greater flexibility with
  its budgets. However, because it is the **employer** who has to pay in the first
  instance, it is possible that the state of their resources may impact on the service
  user irrespective of the flexible financial framework that Access to Work operates
  within.

- **Inconsistency in scope of budgets**: another way in which the organisation of
  budgets could create barriers to a smooth transition was where there appeared
  to be inconsistencies in the scope of budgets. In other words, there were variations
  among service providers managing the same resource as to exactly what a budget
  covered. The variations could be determined at organisation level (e.g. one social
  services department may decide not to include house cleaning within its home
  care service for any users, whilst another may decide to drop house cleaning for
  new users but continue it for current users) or be produced in a much more ad
  hoc way with individual members of staff interpreting eligibility criteria differently.
  Such situations were found among LEAs as to what the DSA was permitted to
  cover, particularly with respect to support for students with dyslexia or mental
  health problems. This could leave two disabled students experiencing very different
  transitions depending on which LEA that they happened to approach. Another
  example involved statementing, where one LEA allowed the release of funds for
  special needs nursery school places and services prior to being statemented whilst
  another did not.

- **Consequences of uncertainty of contract renewal for contracted services**: budget planning could prove difficult for organisations or agencies providing
  services to the local authority under contract, for example, a Direct Payments
  service for a social services department or a transport service for an education
  department. The fear of change of contract or failure to renew contract could
  hinder long-term planning, which could mean contracted providers were unable
  to make long-term commitment to service users and consequently threaten
  disruption to continuity of service.
- **Prioritising (on financial grounds):** due to these financial constraints, sometimes services found their eligibility criteria for services placing increasing emphasis on resources available, which could create barriers. For example, a person wanting to make an accommodation transition may find that they are not able to do so, or there is a delay because they are already in an adapted property, and consequently are of lower priority on a limited OT budget.

- How much funding central and local government allocates to a particular service will determine how much that service can deliver. All services operate within finite budgets and it was a common claim that one victim of this was joint working. Put quite simply, some service providers felt that they only had the resources to carry out their day-to-day work with clients rather than participate in network meetings with colleagues in other, or even related, areas. Furthermore, partnership working sometimes placed an emphasis on having joint aims and pooling budgets but this may not be possible if a service is operating within limited resources. For example, one education department claimed that it could not play a full role in joint working because its financial situation meant that its priorities had to be its statutory functions, one of which was to increase transitions through annual reviews. They argued that partnership working with a provider such as Connexions was possible because increasing transitions through annual reviews was within its remit. However, joint working with organisations that did not share this statutory responsibility, though may have ‘signed up’ to the principle, such as health or social services, would prove more problematic. The consequences of limited or no joint working were far reaching and are evident throughout this chapter.

However, it was not only the level of resources that could create barriers to smooth transitions; the budgetary boundaries or funding structures attached to the funding could also sometimes be restrictive and cause delays in a disabled person receiving a timely service. Where a service provision is ‘shared’ between more than one sector (for example, housing adaptations responsibility shared between social services and housing, or the provision of different types of equipment between health and social services) the division of budget and assessment responsibilities could lead to delays. This ‘sharing’ or division of service provision between different sectors tends to be underpinned by the way that legislation is framed, meaning that it is not possible for local services to run more ‘streamlined’ or ‘pooled’ budgets or service delivery without changes to legislation.

### 6.4 What is being done to address the barriers?

There is, and has been, activity, both at the centre and locally, that attempts to overcome some of these barriers.
6.4.1 Centrally-driven facilitators

In terms of centrally-driven facilitators addressing the barriers, there is a wide range of national policies and initiatives designed specifically to facilitate transitions, and examples can be found within each of the transition types explored in the study, including:

- **Connexions (Careers Scotland’s Inclusiveness Projects - a parallel scheme in Scotland)**, which aims to assist in making smooth and effective transition from childhood through to adult activities such as education and employment. This takes place through the young person working with a Personal Advisor (PA), transition planning, and local level partnership working. While Connexions provides a service to all young people aged 13-19 in England, it has identified young disabled people as a target group. The **APIR** (Assessment Planning Implementation Review) framework, also developed through Connexions, is designed to assist with transition planning and, therefore, in avoiding crisis transitions (discussed further in Chapter 2).

- **New guidelines for delivering housing adaptations** (drawn up jointly by the Office of the Deputy Prime Minister and the Department of Health) which are due to be published in spring 2004 and intend to address the difficulties faced around making housing adaptations. The guidance recommends that there should be a unified team, comprising occupational therapists and housing officials, who agree the way forward for housing adaptations. This should avoid disagreements or difficulties due to misunderstanding between departments that can hinder a smooth transition (discussed further in Chapter 5).

- **Integrating Community Equipment Services initiative** (run within the Department of Health), which aims to bring key agencies (statutory and non-statutory) together in the delivery of equipment to disabled people by pooling equipment stocks and budgets. The initiative seeks to address the difficulties created by the separate provision of equipment by health and social services, including barriers to enabling transitions out of hospital, as well as delays in the delivery of equipment to people with changing needs who are living at home (discussed further in Chapter 5).

- **Access to Work** (managed by the Department for Work and Pensions), which provides advice and practical support to enable a disabled person to make a transition into work (or to stay in work). Through grants, Access to Work pays towards any extra employment costs which result from disability such as specialist equipment to enable an individual to carry out a job or help with travel to work (discussed further in Chapter 4).

- An example of structures in central Government changing to foster closer joined-up working, particularly with respect to provision of joined-up services, is the recent appointment of a **minister for children and young people**, whereby responsibility for children’s policy has been brought together within the Department for Education and Skills.
6.4.2 Locally-driven facilitators

Work has also taken place at the point of delivery by service providers to facilitate transitions. These are explored under the following headings:

- structural facilitators;
- procedural facilitators; and
- budgetary facilitators.

**Structural facilitators**

Adopting different ways of structuring services at the local level has gone some way to breaking down some of the barriers to a smooth transition. The creation of multi-disciplinary teams in specific service areas (although not necessarily across the board) appeared to be a relatively common practice in our case study areas; for example, social services teams and health teams had formed a joint team to look at care provision for mental health service users, or users with learning disabilities. Similarly, there were examples where housing and social services had organised for occupational therapists from social services to be based within a housing team, in order to create a more unified delivery process.

Sometimes services benefited from an actual change of physical location. Having related services, for example, all services working with visually impaired children, housed in the same building means that joint working, liaising and understanding of each other’s roles is more likely, which can be especially useful in crisis transitions where speed can be critical. This approach is taken by Child Development Centres, which bring together health, education and social services providers. A related development is the pilot for Children’s Trusts. The Trusts are designed to co-ordinate children’s services within an area. However, the issue of ‘overlaps’ and simply re-arranging boundaries (discussed earlier) should not be overlooked.

**Procedural facilitators**

In an attempt to address the issue of duplicating assessments, some areas have agreed joint procedures between health and social services to overcome this difficulty whereby, health workers could order certain equipment without requiring a social services assessment.

Some service providers have adopted a very much more proactive approach, for example, speech therapists actively requesting referrals from schools, which has gone some way to ensuring that the correct personnel are involved in the assessment process.

There were also examples of good practice in terms of ensuring that all the information needed for an assessment was being made available. Examples included pupils who were changing school taking with them a record of achievement and a ‘pen picture’ to give to the new school. Another case involved workers from a new day centre visiting the old day centre to see what support the individual received there.
As noted above, crisis or emergency transitions often saw procedures not being followed. There were cases of good practice that endeavoured to avoid such situations. For example, in an attempt to avoid crisis transitions from hospital to home, one housing team operated an ‘open waiting list’ whereby, even if a person in hospital was not going to be looking for housing for three months because they were going into respite care for a while, the team took on the case immediately and started planning the transition.

There was evidence of local service providers designing procedures that would speed up processes without increasing spending. They basically involved reviewing a service and identifying whether there were aspects of it that could be delivered more quickly via a separate mechanism – a sort of ‘two-tier’ system. For example, straightforward assessments carried out by telephone, or quick and easy adaptations carried out on a more ‘quick response’ basis via a dedicated member of staff.

**Budget facilitators**

A further issue concerned the budgetary boundaries which meant that although financial resources existed, they could not be used flexibly and, therefore, may not be most effectively used. However, there was evidence of budgets being employed flexibly to enable transitions. The example cited above, of longer hospital stays as a result of a social services department finding it difficult to meet the service demands of discharge home close to the end of the financial year, is a case in point. The health trust concerned overcame this barrier to the transition by using its budgets more broadly and flexibly to fund the relatively cheap equipment required in order to free the considerably more expensive hospital resource, as they saw it.

### 6.5 Remaining barriers in terms of issues to consider for policy development

The following are suggested areas for policy development applicable across all the types of transition covered in the study (i.e. education, children to adult, employment and accommodation). Areas for policy development specific to particular types of transition can be found within the relevant chapters.

#### 6.5.1 Raise awareness of services

A barrier present in all transition types was the lack of awareness of services available. The lack of awareness was present among disabled people and, perhaps more worryingly, among professionals who then were not in a position to make referrals or signpost services. More worrying still was the lack of ownership as to who was responsible for raising awareness, for example, it appeared to be unclear who should publicise national initiatives and policies. Local service providers seemed to believe that the responsibility lay with central Government as the initiative had a national focus whilst central Government believed the opposite because the initiative would be implemented locally and local service providers were best placed to address this issue.
The lack of awareness of services and procedures involved in accessing services among providers suggests that mapping of local services would be a useful exercise (and this was underway in some areas), especially for newer staff. Also, the lack of awareness among disabled people raises issues of the adequacy of provision of information to potential and current service users. There are issues here for a service in the decisions it makes about channels of promotion and referral routes (i.e. direct access or professional referral procedures).

**Direct Payments**

Direct Payments has features that make it conducive to smooth transitions, for example, as the manager of the service, the disabled person can make a transition and not have to deal with the issues related to change of service provider (this even potentially applies to a move across a local authority boundary although concerns about changes in package of care due to local level needs assessments for Direct Payments still, of course, remain). However, there seems to be low level of awareness of this scheme among service users. One reason for this may be the ‘reluctance’ on the part of the authorities to make the shift from seeing themselves as the direct provider of services or the employer of the service provider.

### 6.5.2 Increase joint working

Whilst there is evidence of joint working with service providers forming multi-disciplinary teams or agreeing joint procedures, there still remains considerable scope for improvement in this area. Where it is lacking it is critical to consider at the design stage how this would affect the implementation of policy.

A further point worth noting is that joint working (be it in the form of working to joint procedures, for example, carrying out joint assessments; operating in multi-disciplinary teams with, for example, shared budgets; or working collaboratively) can entail a financial cost. It cannot always be assumed that, for example, switching from carrying out assessments unilaterally, to carrying them out jointly with a team from another sector will not incur additional cost. Therefore, consideration should be given to allocating funds to cover the resources and time required to develop, pilot, implement, monitor, assess and probably amend joint working procedures.

The consequences of the lack of joint working are acute where a transition involves crossing a local authority boundary because in such cases, all the services that an individual is receiving, as opposed to just the one(s) involved in the transition, are likely to have a change of service provider. For example, for a young person moving out of their parents’ home to their own place but remaining within local authority boundaries, it may mean that some of their service needs remain the same (e.g. they can continue attending the same day centre, receiving weekly treatment from a district nurse), some needs increase (e.g. more transport because the move has taken them further from that day centre), and they receive some new services (e.g. need personal care that used to be provided by their parents). Whereas, a similar transition but across a local authority boundary may mean that they will have a
change of service providers including social services, health, and possibly a contracted transport service provider. Without joint working between the service provider the onus to manage and co-ordinate the transition is on the disabled person or on someone who acts as an unofficial ‘key worker’ (discussed below) on behalf of the disabled person. While this may be appropriate and preferable for some disabled people, it would not be desirable across the board.

‘Key worker’

In some cases, a professional unofficially took on the role of ‘key worker’ and chased and monitored progress. Such practice was found in all the sectors and at all the transition points. This could involve a professional who was not even employed by the service area in which the transition was taking place. Purely based on the strength of the relationship with the disabled person, the professional took on the responsibility of overseeing and ensuring a smooth transition. This approach appeared to be very effective in both easing the experience of the disabled person (in terms of being kept informed and involved) making a transition as well as producing a positive outcome with respect to the transition itself. This would suggest that a more systematic assessment of the potential of a ‘key person’ role merits consideration.

6.5.3 Widen existing initiatives/programmes/policies

There is a range of initiatives, programmes and policies that aim to facilitate smooth transitions including Connexions, Integrating Community Equipment Services initiative, and Access to Work. Some meet this aim more than others, and some have scope for widening their remit to assist more people through transitions. Possibilities include ensuring that disabled young people without a Statement receive the additional support that they need through transitions, widening Access to Work to include support for undertaking voluntary work, broadening programmes that enable individuals into employment to cover self-employment, making public transport more accessible by addressing the issue of routes, and widening the scope of the Single Assessment Process beyond older people.

6.5.4 Develop evidence-based initiatives/programmes/policies

As noted above there is a range of initiatives operating and due to be implemented that aim to enable smooth transitions. A common concern (voiced by respondents from all three stages of the research) was that the ‘need to appear to be innovative’ could mean that new initiatives did not pay adequate attention to existing good practice or build on current effective approaches. The perception that new programmes were continuously being rolled out ‘without regard to what had gone on before’ left some service providers questioning ‘why should this one work when the last one didn’t?’ At the risk of ‘initiative fatigue’, it may be prudent for new approaches to document how they link to, build on, or improve the current position. One tool that would facilitate this is having management information systems in place that can be used to plan, target, monitor progress and assess outcomes of new policies and initiatives.
Appendix A
Methodology

The design and methodological conduct of the study are described in detail below, and are presented in a more summarised form in Chapter 1.

A.1 Selection of the study areas

The fieldwork for the first two stages of the research was conducted in six local authority areas in England, Scotland and Wales. These areas were selected to ensure diversity by the following criteria:

• region;
• level of deprivation according to the Index of Multiple Deprivation\textsuperscript{44} (England only);
• level of rurality;
• authority type (including London Unitary; District/County; Metropolitan; Welsh Unitary, and Scottish Unitary);
• social services star rating (2001, England only); and
• population size.

The authorities used in the study are not specified here, in order to preserve the confidentiality of the respondents that took part.

\textsuperscript{44} DETR published the Index of Multiple Deprivation 2000 (IMD) for England on 2000 http://www.go-wm.gov.uk/regionalIntelligence/deprivation.
A.2 Stage one: in-depth interviews with disabled service users

The first stage of the research was made up of in-depth interviews with disabled service users who had recently experienced a transition in their life.

The aims of this stage of the research were to:

• explore the impact of transitions on service needs;
• examine the nature of any disruption to provision;
• determine factors that made for a smooth or a disruptive hand over of provision;
• focus on the impact of transitions on service provision, rather than on other general barriers or quality; and
• inform the stage two research with service providers.

Stage one consisted of a total of 40 interviews carried out in the six local authority areas. The people interviewed were purposively selected to ensure that a range of characteristics were covered in terms of experience of transitions, disability type, services received, age and sex.

Interviewees were recruited through disability organisations local to the study areas. A letter was sent to a variety of disability organisations with information about the study and who we wanted to interview, and a screening document that could be forwarded to disabled people who may be eligible and interested in taking part. Disability organisations approached potential respondents by other means, such as face to face or over the telephone, where postal contact was not appropriate. Recruitment through disability organisations is a time consuming process. This was particularly the case on this project because the eligibility criteria (disabled people, currently in receipt of services, who had recently experienced a transition and were resident within specific local authority areas) were so complex and narrow.

The profile of the sample of disabled people interviewed is shown in Table A.1.
Many of the disabled people in the sample had experienced more than one type of recent transition, had multiple disabilities, and at the time of the interview were in receipt of a variety of types of services, equipment and support. The high proportion of the sample having experienced educational transitions was expected given that this was the transition type experienced by all the children interviewed.

In the interviews with disabled people, care was taken to ensure that sufficient rest breaks were taken where needed. British Sign Language interpreters were used where required and respondents with cognitive and learning difficulties generally had a carer or advocate present while being interviewed. The interviews with children all involved the children’s parents as well. Interviews took place in respondents’ own homes or somewhere else if the respondent preferred, for example, a few of the interviews took place at a day centre. Respondents to the first stage of the research were given twenty pounds as a token of appreciation for their time.

### Table A.1  Stage one sample profile

<table>
<thead>
<tr>
<th>Structural transitions recently experienced</th>
<th>Total</th>
</tr>
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<tbody>
<tr>
<td>Into, within, out of employment</td>
<td>18</td>
</tr>
<tr>
<td>Into, within, out of education</td>
<td>21</td>
</tr>
<tr>
<td>Change of residence</td>
<td>13</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Disability type</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Mobility</td>
<td>23</td>
</tr>
<tr>
<td>Sensory</td>
<td>17</td>
</tr>
<tr>
<td>Learning and cognitive</td>
<td>10</td>
</tr>
<tr>
<td>Mental health</td>
<td>8</td>
</tr>
<tr>
<td>Chronic ill health</td>
<td>13</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Services received</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical equipment</td>
<td>29</td>
</tr>
<tr>
<td>Support services</td>
<td>32</td>
</tr>
<tr>
<td>Transport services</td>
<td>17</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Sex</th>
<th></th>
</tr>
</thead>
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<tr>
<td>Male</td>
<td>17</td>
</tr>
<tr>
<td>Female</td>
<td>23</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Age</th>
<th></th>
</tr>
</thead>
<tbody>
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<tr>
<td>18-30</td>
<td>5</td>
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<tr>
<td>31-45</td>
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<tr>
<td>46-60</td>
<td>10</td>
</tr>
<tr>
<td>61+</td>
<td>6</td>
</tr>
</tbody>
</table>
A.3 Stage two: in-depth interviews and focus groups with service providers

The second stage of the research was made up of in-depth interviews and focus group discussions with people involved in the delivery of services to disabled people. Providers in statutory provision, and where relevant, providers in other sectors – such as local and national charities or private sector providers - to whom local authorities contract some aspects of support and service provision to disabled people, were eligible for inclusion.

The aims of interviews with service providers were to explore:

- the way in which the delivery of service, support and equipment is organised;
- the ways in which agencies or departments interface;
- areas of ease and difficulty this raises;
- steps taken to aid joint working; and
- perceptions of the factors that impact on continuity of service provision and joint working especially legislative, budgetary, procedural and structural issues.

The focus groups were selected in order to bring together service providers working in a related field and/or with a particular disability type. The aims of the focus groups were to:

- explore further the barriers to service provision during transitions that emerged from the depth interviews; and
- identify strategic solutions to these problems.

Sixty-four service providers participated in the second stage of the research. These respondents were purposively selected to ensure that diversity in the sample was achieved in terms of service delivery areas. In the areas with a district/county council structure, service providers working in each were included. Table A.2 illustrates the range of service provision areas covered in the stage two sample.
Table A.2  Stage two sample profile

<table>
<thead>
<tr>
<th>Service delivery area</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Social services</td>
<td></td>
</tr>
<tr>
<td>e.g. children’s team, disability team, Supporting People staff, Social Services OT managers</td>
<td>13</td>
</tr>
<tr>
<td>Housing</td>
<td></td>
</tr>
<tr>
<td>e.g. adaptation team, LA housing providers, OT managers</td>
<td>9</td>
</tr>
<tr>
<td>Health</td>
<td></td>
</tr>
<tr>
<td>e.g. OT managers, community nurses, psychiatric liaison nurses, rehabilitation workers, speech therapists</td>
<td>8</td>
</tr>
<tr>
<td>Education and training</td>
<td></td>
</tr>
<tr>
<td>e.g. SEN school and nursery head teachers, FE and HE disability officers, educational resources officers, learning support workers, Connexions</td>
<td>16</td>
</tr>
<tr>
<td>Employment</td>
<td></td>
</tr>
<tr>
<td>e.g. DEAs, Access to Work managers, staff from employment-related contracted services</td>
<td>13</td>
</tr>
<tr>
<td>Transport</td>
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<tr>
<td>e.g. mobility services co-ordinators, Dial-a-Ride staff</td>
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</tbody>
</table>

Recruitment for the in-depth interviews involved initially approaching statutory bodies in each local authority area, and from these initial contacts mapping out to include contracted out services. Service providers were sought with both an understanding of budgets, finance and policy issues, as well as, ideally, some contact with, or direct management of staff with contact with, disabled service users. The interviews with service providers made use of case study vignettes derived from the experiences of the service users interviewed in stage one. Each vignette was compiled from the experiences of several service providers in order to preserve confidentiality. Example vignettes are contained in Appendix B.

The focus group recruitment built on the framework developed for the in-depth interview recruitment. The sample selection for the groups aimed to loosely focus on different areas of service provision (e.g. children, employment) and different types of disabilities (e.g. sensory impairments, mental health) in each area. This was done to ensure that the groups were able to explore together relevant aspects of interfacing and could relate to similar barriers and solutions.

Interviews took place at respondents’ place of work, and a local, neutral venue was hired for each of the focus groups.
A.4 Stage three: in-depth interviews with policy officials

The third and final stage of the research consisted of 20 in-depth interviews with policy officials working in central Government departments on disability related policy.

The aims of the interviews with policy officials were to:

- identify recent, current and planned initiatives and ways of working to address the types of issues raised in stages one and two;
- understand the genesis of each and its particular objectives and focus;
- explore the extent to which, and the ways in which, they will address the issues identified in earlier stages; and
- identify gaps, and explore solutions and barriers to those solutions.

The interviews were conducted with policy officials working in the following Government departments:

- Department for Work and Pensions;
- Department of Health;
- Department for Transport;
- Department for Education and Skills;
- Office of the Deputy Prime Minister; and
- Scottish Executive.

Interviews were conducted with policy officials with a sufficient level of seniority to have an overview of the issues and initiatives in their field, whilst also having in-depth knowledge of the issues with respect to the implementation and administration of specific policies. Where two policy officials had overlapping responsibilities for a particular initiative or area of work sometimes they were interviewed together. Interviews took place at respondents' place of work.

A.5 General methods

Consent to be interviewed was obtained over the telephone prior to interview, and a letter was sent confirming the appointment time, venue and the interviewer’s name. Fieldwork took place between September 2002 and May 2003. The interviews and focus group discussions were conducted using a topic guide (provided in Appendix B) and usually lasted between an hour and an hour and a half. The interviews and focus groups were tape recorded and transcribed verbatim.
A.6  Analysis

Verbatim transcripts of all the interviews and focus groups were analysed using Framework, a qualitative analysis method developed at the National Centre and now used widely in social policy research. The method involves ordering and synthesising data within a series of thematic charts. Data from each transcript is then summarised in the appropriate cell, retaining the context and noting the page of the transcript so that the full data can be considered. Organising the data this way means that the full range of experiences and accounts can be explored, and patterns across different groups of respondents can be examined.

Where quotes have been used in this report they are attributed to a respondent described by various characteristics such as gender, disability type and age. All names, and where necessary some other characteristics, have been changed in order to preserve the confidentiality of respondents.
Appendix B
Topic guides

Stage one topic guide for in-depth interviews with adult service users.

Stage two topic guide and example vignettes for in-depth interviews with service providers.

Stage two topic guide for focus groups with service providers.

Stage three topic guide for in-depth interviews with policy officials.
OBJECTIVES
- to identify range of services/equipment/support used and impact on life
- to explore the impact of transitions resulting in a change of service/equipment/support provider and/or in a change of service/equipment/support need
- to examine the nature of any disruption to continuity of provision
- to determine factors that made for a smooth hand over of provision
- to focus on the experience of continuity/discontinuity of provision, not other general barriers or quality of service/equipment/support

TYPES OF TRANSITIONS TO INCLUDE:
- movement into education, training or employment
- change of employer or educational/training institution
- movement out of education, training or employment
- movement between different types of accommodation (including between parental home, independent living, sheltered accommodation, hospital or prison)
- movement between different local authorities and NHS trust areas
- other transitions (including personal transitions such as around age, family and relationships)

TYPES OF SERVICES/EQUIPMENT/SUPPORT TO INCLUDE:
- physical equipment/home and education/training establishment/workplace adaptations
- transport and mobility services
- advocacy/advice/personal support/buddy
- home/residential care/housing support (including meals on wheels, personal care, shopping assistance)
- professional and health services (e.g. physiotherapist, occupational therapist, social worker, key worker)
- communication services (e.g. talking books, interpreters)
- allowances e.g. disabled students allowance (not including benefits)
- vocational/employment support (including support in educational/training institutions)
- other services
1. INTRODUCTION

Introduce self, NatCen/Disability Alliance and the study/DWP

Explain about confidentiality, tape recording and length of interview

Explain need to recap some areas covered by recruitment form, but in more detail

Check respondent is comfortable with:
- length of interview
- how interview will be conducted where third party facilitation is being used
- if rest breaks will be needed
- if there is anything else that can be done to make it easier for them

2. CURRENT CIRCUMSTANCES

The aim of this section is to explore current circumstances and identify relevant transitions.
Follow-up recent transitions identified here in section 5.

Age
Household/family composition/living arrangements who live with
accommodation type/tenure
how long there
where lived before

Current activity
education/training
employment
voluntary work
doing something else

For each activity:
how long doing this
what doing before

Caring responsibilities
children/family members/others

Recreational interests
hobbies and activities
organisation/club/community involvement
Key changes in life over last couple of years, explore:
what happened
how this affected daily life
what impact this had on circumstances and needs
(explore impact of changes in life on equipment/services/suppor in section 5)

CHECK WITH RESPONDENT WHETHER NEED TO TAKE A BREAK

3. NATURE OF IMPAIRMENT/S, DISABILITY/IES, CHRONIC ILL HEALTH

Keep this section brief and focused on current experience of impairments/disabilities/chronic ill health

Explore all disabilities/impairment including chronic illness
sensory impairment (sight, hearing)
mobility/physical impairment
mental health
learning difficulties
cognitive disabilities
facial disfigurement
chronic ill health (e.g. asthma, recurrent heart condition, cancer, symptomatic HIV)

For each type of disability, impairment, chronic ill health:
how long had this
changes over time (stable/deteriorating, constant/fluctuating)
(brief) impact on different aspects of life (home, education, training, work, recreation)

What support currently needed to carry out daily activities

CHECK WITH RESPONDENT WHETHER NEED TO TAKE A BREAK

4. CURRENT USE OF SERVICES, SUPPORT AND EQUIPMENT

Examine provision rather than quality of services

Explore full range of types of services/equipment/support currently used for each impairment, including:
physical equipment
adaptations to home/education/training establishment/workplace
transport and mobility services
advocacy/advice/personal support/buddy
home/residential care/housing support (e.g. meals on wheels, personal care, shopping assistance)
professional and health services (e.g. counsellor, physiotherapist, occupational therapist, social worker, key worker)
communication services (e.g. talking books, interpreters)
allowances e.g. disabled students allowance (not including benefits)
vocational/employment support (including support in education/training institutions)
other services

For each type of service/equipment/support used explore:
purpose
what it is used for
where it is used or located

assessment procedure/history
how first got it
who assessed the need for it
how was the need for it assessed
how long had it

provision
who provides it
(if equipment) who maintains it
who to call if service fails or if unhappy with the service
who pays for it
does it have to be returned

Where receive multiple services/equipment/support, compare assessment procedures
how well it is provided
attitudes towards different providers

CHECK WITH RESPONDENT WHETHER NEED TO TAKE A BREAK
5. TRANSITIONS AND IMPACT ON PROVISION

This section aims to explore the impact of transitions in education, training, work, home or other aspect of life on needs and on continuity of service/equipment/support provision.

How each transition impacted on equipment/service/support needs

For each piece of equipment/service/support
has provider changed
when did change in provider occur
why did change occur
who initiated the change
how long the change took
what was the impact of each transition on provision

For each change in provision (resulting from a transition) explore:
Communication and understanding:
information/communication about the change
understanding of the procedures taking place
understanding of the relationship between different agencies

Experiences of change in provision:
ease or difficulty of change
experiences of disruption or discontinuity
what aspects of provision
what made it disruptive
experiences of smooth hand over of provision
what made it smooth

Whether change in provider affected quality of equipment/service

For each transition experienced, check:
whether any (other) equipment, service or support have now but didn’t have before the transition
whether any (other) equipment, service or support had before the transition but don’t have now
(if new change in provision emerges go back to the beginning of the section)
compare experience of different changes in provision
6. FUTURE TRANSITIONS

This section aims to explore any possible transitions over the next year that might impact on the need for or provision of equipment, services and support.

Awareness of any future transitions that might impact on needs
(explore changes due to transitions only)
how could these needs be met
how might provision be altered/arranged

Awareness of any future transitions that might impact on provision

Whether may avoid any types of transition because of impact on provision

CHECK WITH RESPONDENT WHETHER NEED TO TAKE A BREAK

7. REFLECTIONS AND STRATEGY

This section aims to explore solutions and strategies for improvement

What would have improved the continuity of service/equipment/support provision

What specifically would they like to see happen

Explore what could/should be done
to help people in same situation
recommendations for change

End of interview - Thank the respondent and reassure regarding confidentiality
P6058: PROVISION OF SUPPORT AND SERVICES TO DISABLED PEOPLE

Stage two topic guide: in-depth interviews with service providers

Aims
The aim of the second stage is to explore with service providers:

the way in which service delivery is organised
the way in which each agency or department interfaces with others
the types of transitions that are problematic
the areas of ease and difficulty in interfacing and the types of difficulties this raises
their perceptions of how transitions impact on disabled people’s lives
steps taken to aid joint working
their perceptions of the factors that constrain joint working, particularly legal, budgetary and organisational issues
their views about what can be done to facilitate joint working and to aid continuity of service provision
models for organising the delivery of services and their advantages and disadvantages; and structural and organisational explanations for continuity and discontinuity of provision.

*Types of services/equipment/support include:
physical equipment/home and education/training establishment/workplace adaptations
transport and mobility services
advocacy/advice/personal support/buddy
home/residential care/housing support (including meals on wheels, personal care, shopping assistance)
professional and health services (e.g. physiotherapist, occupational therapist, social worker, key worker)
communication services (e.g. talking books, interpreters)
allowances e.g. disabled student’s allowance (not including benefits)
vocational/employment support (including support in educational/training institutions)
other services

**Types of transitions include:
movement into education, training or employment
change of employer or educational/training institution
movement out of education, training or employment
movement between different types of accommodation (including between parental home, independent living, sheltered accommodation, hospital or prison)
movement between different local authorities and NHS trust areas
other transitions (including personal transitions such as around age, family and relationships)
INTRODUCTION
Self, NatCen, Disability Alliance
The aims of study, DWP, not an evaluation of their service (ensure have understood purpose of interview)
Tape recording and confidentiality
Length of time of the interview
Anything they want to ask before begin

Background information
The aim of this section is to develop a picture of the way in which service delivery is organised including arrangements for joint working with other organisations

Organisations will vary in size and structure therefore explore issues as appropriate

Their organisation structure
Structure of organisation
Where they/their team fits in

Aims of organisation
Who their clients are (disabled, non-disabled)
What they do for them/with them
When and why are the disabled people likely to be in touch with them (e.g. when changes happen in their lives, what sorts of changes)

Joint working
whether work with other teams/departments/organisations (e.g. local voluntary organisations, organisations in other local authority areas, central Government departments)
Exploring impact of transitions using vignettes

In this section use vignettes to explore whether and how the individual’s requirements could be met in their local area and the factors that would help or hinder this.

Using 2 vignettes talk through what the respondent’s role and responsibilities would be.

For each service that is their responsibility to provide
What perceive as the difficulties that the disabled person may face to make this transition
Assessments: what, by whom, how long likely to take
Any difficulties envisage in providing services in terms of following issues:
Legal/legislative/policy
Budgetary/financial
What budgetary systems/boundaries exist in organisation and their influence on helping or hindering transitions
Organisational
What organisational procedures exist within organisation and their influence on helping or hindering transitions
What organisational structures exist within organisation and their influence on helping or hindering transitions
Anything else that helps or hinders transitions
For each difficulty identified how would be resolved

For each service that they have a joint responsibility with another organisation to provide
What perceive as the difficulties that the disabled person may face to make this transition
Joint assessments: what, by whom, how long likely to take
Other joint working involved: what, with whom, how long likely to take
Difficulties envisage in joint working in terms of following issues:
Legal/legislative/policy
Budgetary/financial
What budgetary systems/boundaries exist between organisations and their influence on helping or hindering transitions
Organisational
What organisational procedures exist between organisations and their influence on helping or hindering transitions
Anything else that helps or hinders transitions
For each difficulty identified how would be resolved
For each service that they do not have responsibility to provide
Their role in ensuring disabled person is aware/Attempts to access such services
Difficulties envisage in ensuring this happens, if yes, how would they be resolved

How typical are the scenarios of what they come across (easier or more complicated)

From their experience identify cases where easier (than the scenarios) to organise
What helped make it easier
What would have made it harder

From their experience identify cases where harder (than the scenarios) to organise
What made it harder
What would have made it easier
What makes certain cases easier or more difficult
Type of disability
Type of transition
Type(s) of providers involved (e.g. same sector providers, multiple sector providers, single provider v joint working

Reflections and strategy
Central/local Government policies and agendas (including budgets) that constrain smooth transitions
Practical solutions to overcoming these

Organisational structural factors that constrain smooth transitions
Practical solutions to overcoming these

Procedural and practical barriers to smooth transitions
Practical solutions to overcoming these

Views about whether anything can be done to facilitate smooth transitions when only own organisation involved

Views about whether anything can be done to facilitate joint working to aid smooth transition

Anything else they would like to add

End of interview - Thank the respondent and reassure regarding confidentiality
STAGE TWO EXAMPLE VIGNETTES:

IN-DEPTH INTERVIEWS WITH SERVICE PROVIDERS

Each vignette was tailored to the specific work role of the service provider being interviewed. The vignettes presented below are examples of the types used in the interviews to stimulate discussion of the types of barriers confronted.

A person with physical disabilities, wheelchair user

Recently completed an IT course at FE college where had LSC-funded IT equipment

Has seen a job that would like to apply for

Job involves working in IT section at the head office and travelling to satellite offices

Also plans to move out of parents’ home that was adapted to own flat that has no adaptations

Would like to be able to manage her own care package

A person aged 70, with hearing impairment and learning difficulties

Living independently in another LA

Visits a day care centre for people with learning difficulties, gets assistance with shopping, and is visited by a PA two mornings a week

Wants to move to sheltered accommodation near to where she has relatives

Visually and hearing impaired child aged 5. Has some breathing difficulties and needs oxygen tank to be always available.

Has a social worker and received play and speech therapy at home and at occasional visits to a day care centre.

The family has just moved to a new area.

About to start regularly attending a special needs nursery school 3 days a week.
<table>
<thead>
<tr>
<th><strong>A person who was admitted to hospital as an emergency following a fall</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Is ready to be discharged</td>
</tr>
<tr>
<td>Would like to return to her own home, lives alone</td>
</tr>
<tr>
<td>Will not be able to use the upstairs part of her house</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Visually and hearing impaired person</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Special IT equipment in her office-based job, provided by Access to Work and employer</td>
</tr>
<tr>
<td>Recently had a bad fall, spent time in hospital, going through social services and health assessments to become a wheelchair user</td>
</tr>
<tr>
<td>Wants to move from another local authority to be nearer family</td>
</tr>
<tr>
<td>Will need to find new job nearer her new home</td>
</tr>
</tbody>
</table>
Aim of the focus groups is to:
bring together people from a range of service provision areas (both statutory, and where relevant, providers in other sectors - such as local and national charities or private sector providers - to whom local authorities contract some aspects of support and service provision) who provide a service to a specific disability client group (and in this area it is ……..) in order to explore further the barriers to service provision during transitions* that emerged from the depth interviews and to identify strategic solutions to these problems.

*Types of transitions include:
movement into education, training or employment
change of employer or educational/training institution
movement out of education, training or employment
movement between different types of accommodation (including between parental home, independent living, sheltered accommodation, hospital or prison)
movement between different local authorities and NHS trust areas
other transitions (including personal transitions such as around age, family and relationships)

Introduction
Self, NatCen, Disability Alliance
The aims of study, DWP, not an evaluation of their service
Tape recording and confidentiality
Length of time of focus group
Anything they want to ask before begin

Background
Job title, service sector
Role/responsibilities/client group

From the list of barriers, outline one that reflects the responsibilities of the group participants, explaining that this was identified through the interviews with service providers as an issue/area that acted as a barrier to ensuring a smooth transition of service (repeat using a number of barriers).

Their experience of this barrier

Why barrier arose
How dealt with it - existing solutions
Legislative facilitator
Organisational facilitator
Procedural facilitator
Budgetary facilitator
Joint working facilitator

What would have helped deal with it - new solutions
Legislative facilitator
Organisational facilitator
Procedural facilitator
Budgetary facilitator
Joint working facilitator

If never come across this barrier

Why think not arisen in their experience

How would deal with it if arose
Legislative facilitator
Organisational facilitator
Procedural facilitator
Budgetary facilitator
Joint working facilitator

REPEAT USING OTHER EXAMPLES OF BARRIERS

Any other barriers

Enquire whether have faced any other barriers in ensuring smooth transition of services

What difficulties arose, and why

How dealt with it - existing solutions
Legislative facilitator
Organisational facilitator
Procedural facilitator
Budgetary facilitator
Joint working facilitator

What would have helped deal with it - new solutions
Legislative facilitator
Organisational facilitator
Procedural facilitator
Budgetary facilitator
Joint working facilitator

Any key message would like to send to DWP regarding issues around transitions and joint working

Thank the respondents, re-assure about confidentiality
**P6058: PROVISION OF SUPPORT AND SERVICES FOR DISABLED PEOPLE**

**STAGE 3: TOPIC GUIDE FOR INTERVIEWS WITH POLICY OFFICIALS**

### Aim of interviews

With reference to the types of issues raised in earlier stages, identify recent, current and planned initiatives and ways of working to address these; understand the genesis of each and its particular objectives and focus; explore the extent to which, and the ways in which, they will address the issues identified in earlier stages; and identify gaps, and explore solutions and barriers to those solutions.

### Background

- **Job title, department/organisation**
- **Role and responsibilities**
- **Extent and nature of joint working with other departments, agencies, providers (brief)**

### Difficulties identified by service users and service providers

**Outline an issue identified by service providers as being problematic**
(see list for appropriate issues)
- **Include difficulties and benefits of joint working**
- **Refer to similarities and differences to Scotland and Wales**

### Introduction

- **Self, NatCen, Disability Alliance**
- **The aims of the study, DWP**
- **Tape recording**
- **Confidentiality issues, especially around planned initiatives**
- **Length of interview**
- **Anything they want to ask before begin interview**

Understanding and perception of this issue
Whether issue is seen as a problem
Awareness of **existing** ways of working and initiatives 
(intended to) address this issue
For each existing way of working/initiative intended to/
addressing this issue
In what way
Scope of the initiatives/ways of working
Its genesis, objectives and focus
Extent to which met objectives
What helped it meet objectives
What made it difficult to meet objectives or be implemented
What changes made to make it more effective
What changes should be made to make it more effective

Awareness of **future or planned** ways of working or 
initiatives (intended to) address this issue
For each future or planned way of working/initiative intended 
to/address this issue
In what way
Scope of the initiatives/ways of working
Its objectives and focus
What would help it meet objectives
Any difficulties envisage in implementing them

Where **gaps**, i.e. no existing or planned ways of working or 
initiatives address this issue
Why this is the case
Any suggestions for how policy makers could address this 
issue
What departments should be responsible
What may prevent the issue being addressed

If appropriate - i.e. have not covered this solution -
**present** solution *identified by service users*
Views on it
How implementable
Anything preventing it from being implemented
What needs to be altered/added to solution for it to be 
considered

**Repeat with other issues identified by service providers**
as being problematic

**Any other perceived problems or issues affecting**
continuity of service delivery

**Explore relevant issue identified by respondent as being**
problematic
**include difficulties and benefits of joint working**
**refer to similarities and differences to Scotland and Wales throughout**
For each other problem or issue identified
Understanding of the issue
What makes this issue problematic

Awareness of any existing ways of working and initiatives (intended to) address this issue
For each existing way of working/initiative intended to address this issue
Its genesis, objectives and focus
Extent to which met objectives
What helped it meet objectives
What made it difficult to meet objectives
What changes made to make it more effective
What changes should be made to make it more effective

Awareness of future or planned ways of working or initiatives (intended to) address this issue
For each future or planned way of working/initiative intended to/address this issue
In what way
Scope of the initiatives/ways of working
Any difficulties envisage in implementing them

Where gaps, i.e. no existing or planned ways of working or initiatives address this issue
Why this is the case
Any ideas about how policymakers might address this issue
Any suggestions for how policy makers could address this issue
What departments should be responsible
What may prevent the issue being addressed

Just to check: any other related initiatives and or ways of working

For any other existing initiative or way of working that intends improving provision and/or joint working to help make smoother transitions and overcome the barriers to continuity of provision of services and support including equipment.
Its genesis, objectives and focus
Extent to which met objectives
What helped it meet objectives
What made it difficult to meet objectives
What changes made to make it more effective
What changes should be made to make it more effective
**Future** initiatives or ways of working planned that are intended to improve provision and/or joint working to help make smoother transitions and overcome barriers to continuity of provision of services and support including the provision of equipment.

In what way

Scope of the initiatives/ways of working

Any difficulties envisage in implementing them

**Communication with service providers**

Whether involved providers and/or users in policy development

Any key messages would want to send to service providers to assist them in providing smooth transition through joint working
Other research reports available

<table>
<thead>
<tr>
<th>No.</th>
<th>Title</th>
<th>ISBN</th>
<th>Price</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Thirty Families: Their living standards in unemployment</td>
<td>0 11 761683 4</td>
<td>£6.65</td>
</tr>
<tr>
<td>2.</td>
<td>Disability, Household Income &amp; Expenditure</td>
<td>0 11 761755 5</td>
<td>£5.65</td>
</tr>
<tr>
<td>3.</td>
<td>Housing Benefit Reviews</td>
<td>0 11 761821 7</td>
<td>£16.50</td>
</tr>
<tr>
<td>4.</td>
<td>Social Security &amp; Community Care: The case of the Invalid Care Allowance</td>
<td>0 11 761820 9</td>
<td>£9.70</td>
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<tr>
<td>5.</td>
<td>The Attendance Allowance Medical Examination: Monitoring consumer views</td>
<td>0 11 761819 5</td>
<td>£5.50</td>
</tr>
<tr>
<td>6.</td>
<td>Lone Parent Families in the UK</td>
<td>0 11 761868 3</td>
<td>£15.00</td>
</tr>
<tr>
<td>7.</td>
<td>Incomes In and Out of Work</td>
<td>0 11 761910 8</td>
<td>£17.20</td>
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<tr>
<td>8.</td>
<td>Working the Social Fund</td>
<td>0 11 761952 3</td>
<td>£9.00</td>
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<tr>
<td>9.</td>
<td>Evaluating the Social Fund</td>
<td>0 11 761953 1</td>
<td>£22.00</td>
</tr>
<tr>
<td>11.</td>
<td>Customer Perceptions of Resettlement Units</td>
<td>0 11 761976 6</td>
<td>£13.75</td>
</tr>
<tr>
<td>12.</td>
<td>Survey of Admissions to London Resettlement Units</td>
<td>0 11 761977 9</td>
<td>£8.00</td>
</tr>
<tr>
<td>13.</td>
<td>Researching the Disability Working Allowance Self Assessment Form</td>
<td>0 11 761834 9</td>
<td>£7.25</td>
</tr>
<tr>
<td>14.</td>
<td>Child Support Unit National Client Survey 1992</td>
<td>0 11 762060 2</td>
<td>£15.00</td>
</tr>
<tr>
<td>15. Preparing for Council Tax Benefit</td>
<td>011 762061 0</td>
<td>£5.65</td>
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<tr>
<td>17. Employers’ Choice of Pension Schemes: Report of a qualitative study</td>
<td>011 762073 4</td>
<td>£5.00</td>
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<tr>
<td>18. GPs and IVB: A qualitative study of the role of GPs in the award of Invalidity Benefit</td>
<td>011 762077 7</td>
<td>£12.00</td>
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<tr>
<td>20. Invalidity Benefit: A longitudinal survey of new recipients</td>
<td>011 762088 2</td>
<td>£19.95</td>
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<tr>
<td>21. Support for Children: A comparison of arrangements in fifteen countries</td>
<td>011 762089 0</td>
<td>£22.95</td>
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<tr>
<td>22. Pension Choices: A survey on personal pensions in comparison with other pension options</td>
<td>011 762091 2</td>
<td>£18.95</td>
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<tr>
<td>23. Crossing National Frontiers</td>
<td>011 762131 5</td>
<td>£17.75</td>
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<tr>
<td>24. Statutory Sick Pay</td>
<td>011 762147 1</td>
<td>£23.75</td>
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<tr>
<td>25. Lone Parents and Work</td>
<td>011 762147 X</td>
<td>£12.95</td>
<td></td>
</tr>
<tr>
<td>26. The Effects of Benefit on Housing Decisions</td>
<td>011 762157 9</td>
<td>£18.50</td>
<td></td>
</tr>
<tr>
<td>27. Making a Claim for Disability Benefits</td>
<td>011 762162 5</td>
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