

Guide to Services for Young People with Learning Difficulties/Disabilities and Mental Health Problems/ Challenging Behaviour:

Technical Document -

Chapter 3 Methodologies

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Guide to Services for Young People with Learning Difficulties/Disabilities and Mental Health Problems/Challenging Behaviour – Chapter 3 Methodologies

Four sources of evidence have been drawn upon to produce this Guideline:

- 1) A series of focus group interviews to draw upon the experience and views of a wide range of people involved in a professional or family carer role with the client group
- 2) A programme of in-depth interviews with professionals and family carers by telephone
- 3) A regular programme of meetings with a panel of experts, collectively known as the Guideline Development Group, which has reviewed evidence as well as provided comment and advice on the development of the guide. This guide has also been extensively consulted with a wide group of stakeholders
- 4) An extensive review of the literature pertaining to this client group and to the policies, practices and philosophies that influence transition in the UK.

This chapter describes the methodologies that have been employed for the development of the guide.

1) Fieldwork programme

The Research Fellow Nick Le Mesurier led the fieldwork programme section. The aims of the fieldwork programme have been broadly to scope the issues of concern at transition from a number of perspectives, and thereby to consider

- Individual ‘needs’
- Problems of joint working between services
- Possible solutions
- Uses of Guidelines.

a) Focus Groups

Four focus group interviews were held:

- Practitioners
- Service managers and commissioners
- Family carers
- A ‘mixed’ group drawn from the above.

Recruitment

Recruitment to the first three groups was undertaken either by directly approaching practitioners or senior managers in the West Midlands, or by using a ‘snowballing’ technique to seek recommendations from persons recruited or from organisers of support groups in the West Midlands. Membership of the fourth, ‘mixed’ group was drawn from the first three groups and sought to include a balanced representation from all professions and backgrounds. Groups were each limited to 10 participants and one facilitator, plus administrative support.

Interview techniques.

Interviews were conducted in a room hired for the purpose, participants sitting around a large table, with the recording microphone in the middle. Participants were each assigned a number, which they wore on a lapel badge. This enabled an assistant to keep a written record of who spoke when and said what, which acted as a valuable reference in the transcription process. The project manager facilitated each discussion.

The interviews with Practitioners, Managers and Carers used two short vignettes describing ‘typical’ cases.

Case 1

Peter is a 17-year-old man who has severe learning disability, autism and Tourette’s syndrome, who displays high levels of aggressive behaviour and self-injury. For the last two years he has received a residential treatment service in a rural location, but this must end as he is due to be discharged on the grounds of age. It is the policy of the learning disability services within his home area to avoid out-of-county placements. However, there are no suitable adults’ services available locally. He has limited contact with his parents.

Case 2

Naomi is a young woman age 19 years old, diagnosed as having mild learning disability. Her parents are separated, and she is currently living with her mother, but spending most days with her father in his shop. Naomi is very routine bound, and finds it difficult to adjust to other people. Naomi has epilepsy, which has been severe in the past, but is currently responding well to a new drug regime. Since starting this regime, however, she has begun to display behaviours that have resulted in the termination of her college placement. These have included absconding, flagging down police cars, threatening to jump off bridges, and inappropriate sexual behaviour. Various work experience and day care provisions have been explored for her, but these have each been rejected due to the risks posed by her behaviour. Naomi finds her current circumstances boring, and her parents feel this exacerbates her behaviour problems.

Participants were given copies of the vignettes in advance, along with a brief set of issues to consider in their discussion. Information leaflets, and statements of confidentiality were also provided.

The broad range of issues participants discussed included:

- What are the individual’s needs in each case and how they might be met?
- How might services work together more effectively, and in particular who should lead in each case, and what problems are likely to influence effective joint working?
- How might individuals be helped to express their own preferences and choices?
- What are the risks in each case to the individual, to their family, carers and support agencies, and to commissioners?
- What safeguards are likely to be available, and what could and should be developed?
- How might a guideline assist in joint working?

The ‘mixed’ focus group eschewed the case studies in favour of a short summary of results from previous focus groups and two principal questions:

- What are the essential requirements for good strategic planning for young people with complex health and social care needs moving from children’s to adults’ services?
- Which agency/agencies (and which professional(s)) should be responsible for personal transition plans for young people with complex health and social care needs?

Methods of Analysis.

Each interview was audio taped and fully transcribed. Interviews were thematically coded using Microsoft Word and QSR NVivo. Three people read a sample of the interview transcripts, and comparison of analyses was made.

b) In-depth interviews

The aim of this part of the fieldwork programme was to draw upon a wide range of experience to elicit views on what makes for effective transition planning at a strategic level and for individuals with learning disability and mental health problems.

41 people from a wide range of professions and backgrounds were interviewed by telephone. Respondents were recruited from the following fields, on the basis of their known involvement in transition, and by recommendation (snowballing):

Joint commissioning	(n = 2)
Social services	(n = 4)
Primary care (OT; GP; SALT; Nurse, School nurse)	(n = 6)
Connexions	(n = 5)
Education policy	(n = 4)
Health Policy	(n = 3)
Voluntary sector (Carers support; MENCAP)	(n = 3)
Advocacy	(n = 1)
Valuing People Support Team	(n = 1)
Academic Research	(n = 3)
Psychiatrist for LD	(n = 5)
Teacher	(n = 2)
Clinical Psychologist	(n = 1)
Parent and author on transition	(n = 1)
 Total	 (n = 41)

Semi-structured interviews have been conducted using a topic guide consisting of a series of issues that have emerged in the course of focus group interviews and data obtained in GDG meetings. The function of the topic guide is to prompt discussion rather than to obtain specific data: to discuss freely their experience and points of view, and to offer their opinions on a variety of issues, rather than give factual information or corporate data.

The initial questionnaire consisted of a number of primary topics or themes, and a series of subsidiary ones under each heading. This quickly proved too complex and inhibiting to the natural flow of the interview, and was dropped in favour of a few broad and open themes that allowed people to respond freely.

These covered:

- The respondent's own involvement in transition planning
- Their views on what constitutes and is necessary for good transition planning at the strategic level (if appropriate) and when working with individuals.

Examples of good practice

Responses were recorded by handwritten notes. As far as possible verbatim statements were recorded, though the majority of data consists of summary notes by the researcher. These were written up as Word files, and transferred to NVivo for thematic analysis.

The codes used to identify themes were derived from the topic guide and expanded as themes as emerged in the course of analysis. The 'code tree' as this structure is known is presented as Appendix A.

Data under each code were read and key themes summarised.

2) Guideline Development Group

An important part of the process of developing the Guide has been the contributions made by members of the Guideline Development Group. Members of this group have met monthly to inform the research team on aspects of the transition process and comment on evidence and on the development of the guide. The process is iterative. Meetings started in January 2005 and ended in December 2005.

Membership of the group consists of the following people:

Organisation	Role	Name
Leicestershire Partnership NHS Trust	Director of Learning Disability & Specialist Mental Health Services	Clare Cunningham
Tuberous Sclerosis Association	Parent Carers	Hilary McGlynn
Solihull Mental Health Trust	Joint Commissioner	Brenda Calvin
Strategic Health Authority – Birmingham and Black Country	Learning Disabilities Programme Lead	Fiona Ritchie
Oxfordshire LD Trust	Medical Director and Consultant Psychiatrist	John Morgan
South Birmingham PCT	Provider Mangement	Alison Thompson
University of Birmingham School of Education	Senior Lecturer	Dr Penny Lacey
Sunfield School	Family Support Manager	Sally Conway,
W Midlands SEN Regional Partnership	Regional facilitator	Bridget Jones
Operations Manager	Connexions, Birmingham & Solihull	Martin Fleet
Operations Manager	Connexions Wolverhampton	Rosemary Robbins
Performance and Development Manager, Worcs Learning Disability Service	Social Services /	Chris Sholl
LD Services, Solihull	Adult Team manager,	Anna George
Autism West Midlands and Family Carer	Voluntary Sector	Linda Woodcock
CEO and Carer	Way Ahead Services	Ray Smart
North Warwickshire PCT	Psychologist for young people with LD	Dr. Alan Richens
North Warwickshire PCT	Consultant Psychiatrist for adults with LD	Dr Ashok Roy
North Warwickshire PCT	Consultant Psychiatrist for children with LD	Dr. Pru Allington-Smith
Leicestershire Partnership NHS Trust	Consultant Psychiatrist for adults with LD	Dr Sabyasachi Bhaumik
St George’s University College Hospital	Consultant Psychiatrist for children with LD	Dr. Jane McCarthy
South Staffordshire PCT	Nurse Manager	Ruth Kirkman
Transition Lead	Valuing People	Linda Jordan
Mental Health Lead	Valuing People	Ken Holland

Discussions within the GDG meetings were organised around a framework designed in its very first meeting in order to provide structure to the meetings and to help define

the roles of the various organisations involved in transition and the relationships between them.

The following framework included a series of headings, arranged in three groups:

‘Planning at the local level’ refers to issues of strategic planning for health, education and social care for this group of people.

‘Planning at the person level’ refers to issues of planning for and with individuals and their families / carers to support physical, emotional and social well-being from childhood / adolescence into adult life.

‘Service user and carer issues’ refers to mechanisms by which the wishes, rights and concerns of these people are fully represented and have effect in the transition process.

Planning at the local level (strategic planning).

- Define ‘local level’.
- Define the organisations involved.
- Define the ‘population’ for which planning is needed.
- Describe the mechanism for planning (assessment of local population needs; resource planning; time scale for planning).
- Define the boundaries among the organisations (Roles, responsibilities, accountabilities, legal positions of the organisations).
- Relationship with other strategies and protocol (national and local) (e.g. VP, NSF, care pathway etc.).
- How & which organisation(s) take(s) lead in local planning.
- How to facilitate joint planning (e.g. understanding of different rules and culture within different organisations).
- How to use the epidemiological data (e.g. who needs to know & what is done with the data etc.).
- Implementation of the planning.
- Build up relationship between commissioners & providers (e.g. fact-finding away days; training etc.).
- Quality control, monitoring, audit, performance indicators etc.
- Training issues.

Planning at the person level

- Roles, responsibilities, accountability of the agencies.
- Roles, responsibilities, accountabilities of the professions in co-ordinating care plans (key worker etc.).
- Facilitation of joint working.
- Assessments (refer to the West Midlands Transition Care Pathway)
- Areas to cover.
- Time frame.
- Professional involved.
- The process involved,
- Existing tools/ checklists.
- Standardise assessment procedure/ minimise repetition.
- Community care assessment, carer assessment, continuing care eligibility etc.
- Sharing information (care plan) among professional, service users & carers.

- Existing protocols & checklists
- Care pathway (West Midlands).
- CPA (& children's equivalent of CPA).
- Green light toolkit.
- PCP
- HAP
- Reconcile different work practice involving different agencies & professions.
- Overlap with other services (e.g. generic, forensic, children's service, private provider, voluntary sector etc.)

Service user & carer issues

- Procedure to ensure service user & carer involvement & influence on the planning of care at pre-transition, transition & post-transition stages.
- Preparation.
- Information sharing regarding resources at local & national levels (local & national databases).
- Information sharing on eligibility criteria, rights, rules & regulations.
- Reconcile carer's desire against available resource.
- Service user consent & capacity issues.
- Preparation.
- Information sharing.
- User-friendly way of information sharing.
- Reconcile service users', carers' & professionals' views on needs & resource planning.

Although discussions in the GDG meetings took place around the above framework, the recommendations were produced under the following eight broad themes:

Strategic planning at the local level

- Joint planning.
- Roles and responsibilities of the agencies involved in transition planning process
- Assessment of overall needs.
- Assessment of mental health needs.
- Involvement and empowerment of young people with learning disability and their family/carers.
- Sharing of information.
- Person Centred Planning.

The Principal Investigator (Professor Shoumitro Deb) led discussions in GDG meetings. Notes were taken on flip-charts and points agreed at each meeting. They were then written up as minutes and circulated for comment. Two presentations were also received:

- 1) from an audit of needs and services for young people with learning disability in Leicestershire
- 2) a Connexions led service in Somerset.

In addition to discussion on these topics, consideration was given to evidence obtained from literature and from primary data collection. This formed the main focus of discussion in the remaining meetings.

3) Stakeholders

A number of people were invited to become ‘stakeholders’ in the project. The role of stakeholders was primarily to comment on drafts of the Guide as it developed, though many also contributed interviews as part of the Telephone Interview Programme.

Stakeholders included:

Organisation	Named contact person	Role
Autism West Midlands	Carolyn Bailey	Chief Executive
Brian Oliver Centre- Brooklands Hospital	Dr P. Allington Smith	Consultant Psychiatrist
British Institute of Learning Disabilities (BILD)	Lesley Barcham	Learning Development Manager
Cardiff School of Social Sciences	Dr Lindsay Prior	Professor of Sociology
Connexions, Birmingham and Solihull	Mr Martin Fleet	Operations Manager
Connexions, Wolverhampton	Ms Rosemary Robbins	Operations Manager
Foundation for People with Learning Disability (FPLD)	Jill Davies	
Home Farm Trust	Margaret Power	Assistant Carer Support Officer
In Control project	Simon Duffy	project leader
Institute of Child Health - Birmingham Children's Hospital	Janet E McDonagh	ARC Senior Lecturer in Paediatric and Adolescent Rheumatology
Estia Centre, Guys Hospital	Prof Nick Bouras	Consultant Psychiatrist
MENCAP	Ms P. Johnson	District Officer
National Institute for Mental Health in England East Midlands	Fiona Gale	Director East Midlands NIMH
Norah Fry Research Centre	Dr Pauline. Heslop	Research Associate
North Warwickshire PCT	Mr M. Saunders	Manager Learning disability Services
North Warwickshire PCT - Brian Oliver Centre-Brooklands Hospital	Dr Ashok Roy	Consultant Psychiatrist
Prudhoe Hospital	Ms K. Thompson	Northgate & Prudhoe
Real Lives, Real Choices (advocacy)	Jenny May	Chairperson , advocacy worker
Special Education Needs, Regional Partnerships, West Midlands	Ms Bridget Jones	Regional facilitator
St. George's Hospital Medical School	Dr. Jane McCarthy	Consultant Psychiatrist
Solihull PCT	Ms Brenda Calvin	Joint Commissioning Manager-Learning Disabilities
Strategic Health Authority - West Midlands South,	Fiona Ritchie	Learning Disabilities Programme Lead
Strategic Health Authority - Birmingham and the Black Country	Jane Bakewell	Programme Development Manager for Mental Health

Sunfield School	Prof. B. Carpenter / Gill Harvey / Ms Sally Conway	Chief Executive and Principal / Transition Manager / family support manager
Tamworth CLDT	Ms Ruth. Kirkman	Senior Nurse
Tizard Centre, University of Kent at Canterbury	Sarah Axtell	Research Fellow
University of Birmingham- Health Services Management Centre	Dr Jon. Glasby	Senior Lecturer
University of Birmingham - School of Education,	Dr. Penny Lacey	Senior Lecturer
University of Birmingham School of Psychology	Prof. Chris Oliver	Professor of Clinical Psychology
University of Lancaster-Institute for Health Research (Learning Disability)	Prof. Eric. Emerson	Professor of Disability and Health Research
University of Ulster	Prof. R. McConkey	Professor of Developmental Disabilities
Valuing People Support Team	Mr Ken. Holland	lead on mental health issues
Valuing People Support Team	Ms Linda. Jordan	lead on transition
Valuing People Support Team	Ms Zoe. Porter	Liaison for whole VP team
Walsall PCT	Ms Andrea. Price	Senior Practitioner for Transition
Welsh Centre for Learning Disabilities	Stephen Beyer	Deputy Director, Welsh Centre for Learning Disabilities
West Sussex PCT	Mark Hardcastle (Recommended by Jane McCarthy)	Nurse Consultant for Adult Mental Health Services in West Sussex
Worcestershire mental health partnership trust	Mr A. Richens / Helen Bradley	Psychologists
Worcestersire SSD Adults with LD Social Work Team (SSD)	Mrs Natalie Lakenby	Social Worker (Transition)
White Top Research Unit, University of Dundee	Maureen Phillip	Researcher

4) Literature Search

A literature search was performed to locate relevant published material.

a) **Methods employed in searching the literature**

A systematic review of the literature initially surveyed academic databases according to the following themes:

- Learning Disabilities
- Mental Illness

- Young people/adolescents
- Services.

A number of databases were scanned including CINAHL, PsychInfo and IBSS (BIDS). They were each searched using the same review criteria. The keywords employed in these searches included those shown in Table 1 below:

Table 1

Disabilities	Mental illness	Age	Services
Mental* disab*	Mental health	Transition	Service*
Mental* retard*	Mental* ill*	Young people	Care*
Mental* impair*	Mental* disorder*	Adolescen*	Support*
Intellect* disab*	Psychiatric Disorder*	Age 14 - 25	School*
Intellect* impair*	Psychiatric ill*	Child*	Educat*
Intellect* deficienc*	Psych*		Review*
Development* disab*	Depress*		Transition*
Mental* handicap*	Mood disorder*		Plan*
Learning disab*	Personality disorder*		Social*
Learning difficult*	ADHD		Program*
Learning disorder	Autis*		
	ASD		
	Challenging		
	Behaviour		
	Behaviour*		
	disorder*		

A search of the CINAHL database revealed 216 papers of relevance when using and combining the following search terms (see Table 2).

Table 2

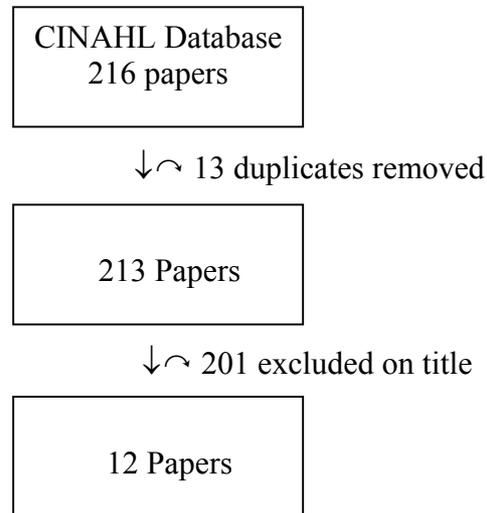
CINAHL	Records
1. Learning disab\$ OR mental disab\$ OR mental retard\$ OR learning disorder OR intellect\$ disab\$	1993
2. mental\$ disorder\$ OR mental health OR psychiatric disorder\$ OR behavio\$ disorder\$ OR behavio\$ problem\$	8664
3. transition OR adolescen\$ OR age 14-25	63962
4. service\$ OR plan\$ OR care\$ OR educat\$	67840
Combine	216

Inclusion Criteria - papers published between 1990 and 2005.

Exclusion Criteria - Age under 14 or over 24 years, and: Not related to mental health

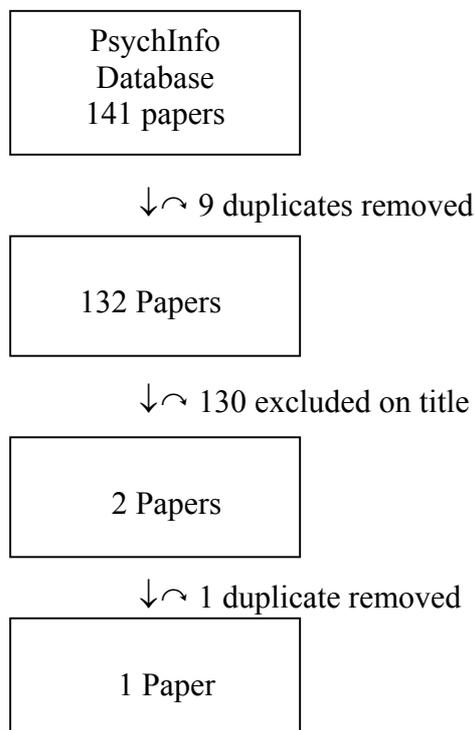
Of these 216 papers identified through a search of the CINAHL database, 12 were identified as relevant for the purposes of the project. The process of selection for these papers is presented in the figure below.

Figure 1: A breakdown of the selection process for the papers identified by CINAHL



A similar search of the PsychInfo database revealed 141 papers published between 1990 and 2005. The same keywords were used as for the search of the CINAHL database (see Table 2 above). Of these 141, 1 paper was identified as relevant for the purposes of this project. The process of selection for this paper is presented in the figure below.

Figure 2: A breakdown of the selection process for the papers identified by PsychInfo



A final search was conducted on the International Bibliography of Social Sciences (IBSS) database. This database does not allow results from separate searches to be combined. Therefore, selection of papers from each search was made through a scan by eye for relevance. Any duplicates were removed. The table below notes the keywords used for each search, the number of papers this produced and the number of papers identified as relevant. This search was carried out for papers published between 1999 and 2005.

Table 3

Keywords used for each search.	Papers identified.	Relevant Papers
Learning disab* AND adolescent*	16	2
Learning disab* AND mental health	40	2
Learning disab* AND transition	6	1
Mental* retard* AND service*	9	0
Learning disab* and behavio* disorder*	0	0
Intellect* disab* AND behavio* disorder*	0	0
Learning disab* AND age 14-25	0	0

Mental* retard* AND age14-25	0	0
Psychiatric disorder* AND 14-25	0	0
Behavio* disorder* AND age 14-25	0	0
Intellect* disab* AND age 14-25	0	0
Mental health AND age 14-25	0	0
Learning disord* AND age 14-25	0	0
Mental* disab* AND age 14-25	0	0
Transition AND services	247	5
Intellect* disab* AND transition	4	0
Learning disab* AND service*	52	5
Learning disab* AND behavio* disorder* AND service*	0	0
Behavio* disorder* AND intellect* disab* AND transition	0	0
Behavio* disorder* AND service*	8	0

A further search was also carried out for papers published between 1990 and 1999.

Table 4

Keywords used for each search.	Papers identified.	Relevant Papers
Learning disab* AND adolescent*	4	0
Learning disab* AND mental health	12	0
Learning disab* AND transition	1	0
Mental* retard* AND service*	4	1
Learning disab* and behavio* disorder*	0	0
Intellect* disab* AND behavio* disorder*	0	0
Learning disab* AND age 14-25	0	0
Mental* retard* AND	0	0

age14-25		
Psychiatric disorder* AND 14-25	0	0
Behavio* disorder* AND age 14-25	0	0
Intellect* disab* AND age 14-25	0	0
Mental health AND age 14-25	0	0
Learning disord* AND age 14-25	0	0
Mental* disab* AND age 14-25	0	0
Transition AND services	63	0
Intellect* disab* AND transition	0	0
Learning disab* AND service*	24	1
Learning disab* AND behavio* disorder* AND service*	0	0
Behavio* disorder* AND intellect* disab* AND transition	0	0
Behavio* disorder* AND service*	3	0

Altogether, a systematic search of CINAHL, PsychInfo, and IBSS databases found 30 papers that were judged by their title to be of relevance. Of these, 3 more papers were excluded according to its abstract, leaving 27 papers to be included in the literature review.

Searches using the methods described above provided few papers of relevance. A more fruitful approach was to undertake a hand search using 'Scholar Google' to search for individual papers, searches and interrogation of literature from key agencies in the field, such as Norah Fry Research Centre and the Foundation for People with Learning Disabilities. Much of this literature would be classified as 'grey' literature that refers to specific projects or evaluations, and includes books and book reviews, 'in-house' reports, guides and other service oriented literature. These were collated by hand under various themes, and duplications removed.

A number of journal websites and relevant websites were also searched for relevant material. These searches found many additional research reports as well as guides for families, service users and professionals. Table 5 summarises the websites searched and the number of relevant papers that were identified

Table 5

Website	Relevant Papers/ Reports/Guides
http://www.learningdisabilities.org.uk/page.cfm?pagecode=PUAP	12
http://www.bris.ac.uk/depts/NorahFry/	8
www.nas.org.uk	2
www.jrf.org.uk	1
http://www.mencap.org.uk/	1
http://www.rcpsych.ac.uk/campaigns/partnersincare/parentschecklist.aspx	2
http://www.ingentaconnect.com/content/bpl/bjsp	4
http://www.ingentaconnect.com/content/bsc/bld;jsessionid=j6fck77ofnea.alice	6
http://www.ingentaconnect.com/content/bsc/jar	5
http://www.aamr.org/	5
http://pb.rcpsych.org/	3
http://www.blackwell-synergy.com/loi/jir	5

In order to identify some of the legislative framework relevant to transition planning for young individuals with learning disabilities and additional problems, a hand search was performed of the Department of Health website. A search of the following sites produced 17 documents of importance for our project.

Table 6

Website	Relevant Papers/ Reports/Guides
http://www.dh.gov.uk/PolicyAndGuidance/HealthAndSocialCareTopics/fs/en	10
http://www.dh.gov.uk/PublicationsAndStatistics/LettersAndCirculars/HealthServiceCirculars/fs/en	1
http://www.dh.gov.uk/assetRoot/04/05/72/70/04057270.pdf	1
http://www.dfes.gov.uk/	5

The relevant acts of parliament were also identified through a search of the HMSO (<http://www.opsi.gov.uk/acts.htm>) website. This search resulted in 11 relevant acts of parliament.

A final 10 research papers and guides were identified through a search of the reference lists of some relevant papers.