

# **Review of Learning Disability Nursing Research 1995 – 2003**

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## 1. Introduction

This is a report of a review of research published by learning disability nurses, and about learning disability nursing, between 1995 and 2003. The review was generously funded by the General Nursing Council for England and Wales Trust.

The origin of the review lies in a conversation between two of the authors (Ruth Northway and Duncan Mitchell) at the Royal College of Nursing (RCN) Research Society Conference in Manchester in 2003. Learning disability nursing is a very small part of the nursing profession but it nevertheless appeared to be under represented at nursing research conferences. However the apparent gradual rise in the number of learning disability nurses presenting papers at the RCN conferences suggested that there was a growing amount of learning disability research being carried out within nursing. Nonetheless, this apparent growth in activity was difficult to quantify and in order to rectify this a research proposal was submitted to and accepted by the General Nursing Council for England and Wales Trust.

This report contains a background literature review that places the work within the context of nursing research in general and learning disability nursing research in particular. The review discusses the apparent lack of usage of research among many learning disability nurses and draws attention to the difficulties that practitioners experience in accessing research information. The review also highlights that until now there has not been a comprehensive review of the research undertaken by, or about, learning disability nurses.

Following a statement of the research objectives, section four of the report details the study design. This consisted of a five-stage search process followed by analysis. Results of the analysis are described in section five and this is followed by discussion in section six. Conclusions are then drawn and recommendations for further work made.

A summary of the findings are that:

- The identification of learning disability nursing research via the use of electronic databases can be complex and the use of multiple databases and multiple search terms is required.
- 142 research papers originating from the United Kingdom or Ireland were published by learning disability nurses or about learning disability nursing between 1995 and 2003.
- There were a number of key themes, broadly categorised into: educational and professional developments; health care experiences; service development and delivery; challenging behaviour; methodology; role of the nurse; historical research; therapeutic intervention.
- An additional 14 papers were published by, or concerning, nurses working with people with learning disabilities outside of the UK or Ireland. The key themes evident in these papers were categorised into: family care; nursing care; the experience of health care; educational and professional development; and service development and delivery.
- Whilst there were a range of methodologies used, a large number were small-scale studies.

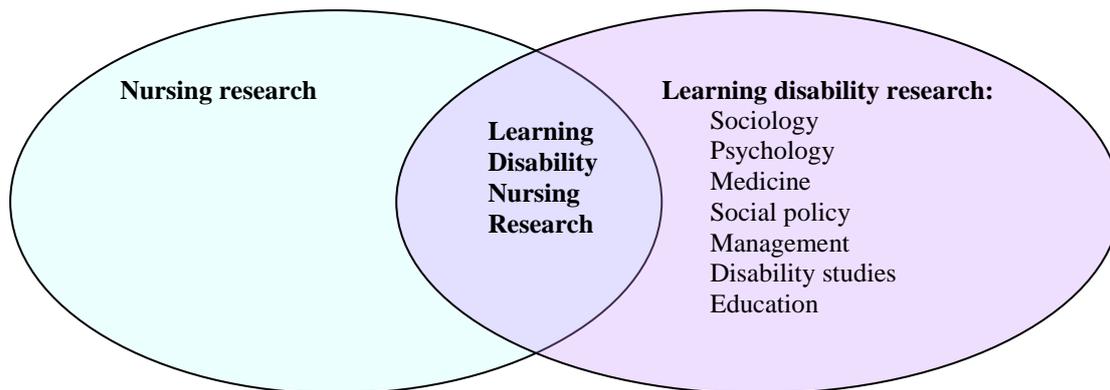
- Only a minority of papers reported a funding source for the research.
- A significant number of papers were published in international nursing journals but very few were published in key international learning disability journals.
- There were wide differences in the use of key words.
- There was a growth in the amount of research over the study period although the rate remained steady between 1998 and 2003.
- Papers were published in a total of 31 journals.
- There was a lack of synthesis between areas of research that are relevant to learning disability nurses.
- There appeared to be no consensus about key texts, or reference to a body of learning disability nursing work within the literature.

## 2. Background literature review

The need for practice to be evidence based has been widely stressed in numerous professional policy documents. Indeed the Nursing and Midwifery Council (NMC) Code of Conduct (2004) states that all nurses have ‘a responsibility to deliver care based on current evidence.’ Whilst clinical expertise and the preferences of service users also influence professional decision making (Gates and Atherton, 2001), and a knowledge and understanding of research is only one component of critical practice (McSherry *et al*, 2002) and evidence based decision making (Flemming and Fenton, 2002), the NMC does stress that validated research should be used ‘when it is available.’ It is thus of concern that Parahoo *et al* (2000) found that whilst the learning disability nurses taking part in their study generally reported a positive attitude towards research, only a quarter of their sample of 87 nurses stated that they used research frequently, or all the time in their practice. Respondents cited a lack of awareness and a lack of access to research information as reasons for this lack of use.

Difficulties in accessing research information amongst learning disability nurses are also reflected in the experience of the authors of this report who have found that students at both pre and post registration levels often complain of problems in identifying learning disability nursing research. In part this appears to be a difficulty arising from the wide range of terms used to refer to the client group with whom learning disability nurses work since terminology has changed greatly over recent years, and also varies from one country to another. Nurses also report problems in identifying what they consider to be relevant research when searching computerised databases. Muir Gray (2001) refers to this as the ‘hunting gap’ in the evidence and attributes it to the limitations of electronic databases and inadequate indexing.

Parahoo *et al* (2000) suggest that there has been proportionally less research carried out within learning disability nursing, as compared with other branches of nursing. This would seem a reasonable assumption given that learning disability nursing is numerically one of the smaller branches of nursing and the limited research in this area has been noted by other authors (for example Kay, 1995; Turnbull, 1997; Mitchell, 2004; Moulster and Turnbull, 2004). Nonetheless it is also noted that learning disability nursing draws upon a number of other academic disciplines for its evidence base (Kay, 1995; Gates and Atherton, 2001; Mitchell, 2004) and since it is part of the wider family of nursing, research undertaken in other fields of nursing will have relevance. Learning disability nursing may thus be seen as being at the interface between different academic and professional disciplines (see Figure 1 below) and an examination of factors influencing the development of research in nursing and in learning disabilities identifies some factors which may explain the limited research specifically in the area of learning disability nursing.



**Figure 1: The position of learning disability nursing research**

Nursing research is viewed as being at ‘a relatively early stage of development’ (Task Group 3, 2001). Whilst one study (drawing upon bibliometric analysis) noted an increase in published research papers in England over the previous 10 years it also noted that outputs in nursing and midwifery had not increased since 1995 (Centre for Policy in Nursing Research *et al*, 2001). Furthermore it reported that a high proportion of papers (73%) did not indicate a funding source for the research implying that the studies had been self funded. The need to provide better financial support for nursing research (both in relation to project funding and infrastructure development) has thus been noted (Task Group 3, 2001).

The overall report of the 2001 Research Assessment Exercise (RAE) Nursing and Midwifery Panel (Unit of Assessment 10, 2001) did note some positive developments in relation to nursing research most notably the increase in the number of submissions, the improvement in the proportion of submissions achieving a higher grade, and an increase in the number of staff submitted. They also commented upon increased institutional investment in research and upon some ‘relatively solid’ areas of research in relation to mental health, care of older people, cancer, heart disease, palliative care, pain management and maternity care. However, problems were also identified which included funding levels and sources of funding, underdeveloped collaborations around research topics, and research programmes which were fragile due to high levels of staff movement. Overall it was concluded that:

‘The sector is growing well in spite of many challenges and is producing some work of real relevance to national priorities. To reach the next stage of development it needs an injection of funds to support the growth of national and international quality work, and to develop research capacity

until it is in line with the size of the sector in higher education' (Unit of Assessment 10, 2001:6)

Learning disability nursing is no different to other branches of nursing in drawing upon other professional and academic disciplines to inform its evidence base. Indeed Chinn and Kramer (1999) suggest that as the educational preparation of nurses developed 'Problems in nursing practice for which there had seemed no ready solution began to be viewed as resolvable if theories from other disciplines were applied' (p32). They caution, however, that whilst such theories may be useful they should not be 'arbitrarily' applied since they may not take into account factors which may significantly influence nursing practice. A similar stance is taken by Munhall (2001) who, whilst acknowledging that nurses draw upon other disciplines, distinguishes between what she terms first and second order activities. The former she views as encompassing those activities concerned with 'coming to know, discovering and understanding' whilst the latter are concerned with 'validation and verification'. Problems are seen as arising where 'the first and second order activities are not from the same world or discipline' (p39) since 'the inquiry will not be logically consistent or experientially valid'.

Learning disability nurses do, however, work in an environment in which emphasis is placed on the need for multi-disciplinary and inter-disciplinary working than is the case in some areas of nursing. Indeed, as a key report concerning learning disability nursing acknowledged, no single profession is capable of meeting all the needs of people with learning disabilities (Kay *et al*, 1995). The need to share knowledge and to develop new knowledge in partnership is thus evident.

Nonetheless if the wider field of learning disability research is considered, some factors can be seen which may negatively impact upon the quantity and quality of research in learning disability nursing. Back in 1958 Clarke and Clarke observed that learning disabilities had, traditionally, always been a neglected area of study and some 25 years later Digby (1996) commented that the 'social marginality' of people with learning disabilities has been mirrored by their 'academic marginality'. Turnbull (1997) also notes learning disability research has never been viewed as a priority for governments despite significant government resources being used to provide support for this client group. Perhaps these reasons may contribute to the situation described by Parmenter (2001 p191) in which many interventions used in the field of learning disabilities are 'of uncertain value and which have never been tested'.

Research in relation to people with learning disabilities can present methodological challenges. For example McConkey (1998) highlights three key areas of difficulty in relation to good quality research in this field. First he notes difficulties which arise due to the heterogeneity of the population to whom the label learning disability is applied and the use of imprecise definitions. Obtaining an adequate sample may thus be problematic and this, in turn, may lead to difficulties in being able to generalise from findings. Second he suggests that the measures used in studies are rarely tested for reliability and validity. Finally he identifies that few longitudinal studies are carried out: changes over time may thus be difficult to determine.

From her review of research in the field of learning disabilities Allen (1997) identified three main types of research – local investigations or evaluations, epidemiological

research and large-scale investigations. She notes limitations in relation to evidence of 'tenuous' relationships between the needs of the researcher and those of people with learning difficulties, an absence of information as to how the permission of people with learning disabilities was obtained when they acted as research subjects, and duplication of work. She makes the point, however, that 'duplication' should not be confused with 'replication' which would be an important and valid scientific process. Her conclusion is thus that 'research into learning disability is, by and large, not co-ordinated, work is disparate and therefore fails to address the immediate health needs in the lives of people with a learning disability in a focused way' (p360).

McConkey (1998) identifies 3 key areas upon which he feels learning disability research should focus. First he suggests that the impact which the family and the community have on the person with a learning disability should be an area of investigation. Next he suggests that service interventions should be evaluated – what do staff do which makes a significant impact on the lives of people with learning disabilities and their families? Finally he advocates that information should be gathered concerning intended and unintended service outcomes.

In relation to research in the field of learning disabilities questions have been raised not only in relation to what is researched but also as to the approaches and methods used. As Gates and Atherton (2001) argue, gathering evidence regarding effectiveness should include seeking the views of people with learning disabilities themselves and the issue of evidence based practice needs to be considered alongside empowerment and service user involvement. Similarly McConkey (1998) argues that we should consider how the perceptions which professionals hold in relation to benefits of outcomes and quality standards compare with those of service users. However, as Walmsley (2001 p188) notes, research in relation to people with learning disabilities has traditionally 'tested, counted, observed, analysed, described and frequently pathologised but never asked for their views'. In response to such a situation recent years have seen the promotion of more participatory, emancipatory or inclusive forms of research in learning disability research generally (see for example Ward, 1997; Kiernan, 1997; Chappell, 2000) and also, more specifically, in relation to learning disability nursing research (see for example Richardson, 1997; Northway, 2000; 2003). However, whilst it is noted that a number of key funding bodies insist on the inclusion of people with learning disabilities as a condition of funding (Gilbert, 2004; Walmsley, 2004) elsewhere it is argued that securing funding for emancipatory research has been problematic (Hanley, 2005)

It can be seen from the preceding discussion that both nursing research and wider research in relation to people with learning disabilities are relatively small and developing areas of academic study which have in common access to limited funding. This presents some key challenges for learning disability nursing research which operates at the interface between these two areas. It may be difficult to access funding since such resources are often linked to whether a particular research project is considered to belong to a specific subject area or not (Mitchell, 2004). Learning disability nurses may thus find themselves encouraged by funders of nursing research to seek support from social science sources whereas social science funders may be reluctant to support nursing research as it is not viewed as 'true' social science or learning disability research if it is not identified as a priority area. Learning disability nurses will also always be a small group within both the wider family of nursing and

also within the wider, interdisciplinary field of learning disability and hence their numerical power and influence may be limited. An understanding of the political nature of research funding and a willingness to engage in a political process are thus required.

Access to funding, however, may not be the only factor which limits the development of learning disability nursing research. Research will only develop if there is an interest in, and commitment to this occurring from within the profession. It is thus interesting to note that a key report concerning learning disability nursing (Kay *et al*, 1995) only briefly mentions the need for nurses to use theoretical and research based knowledge to inform practice development rather than identifying the need to use research and generate new knowledge as a core skill of learning disability nurses. This despite the fact that, in the same year, one of the authors of the report had noted elsewhere the need for learning disability nursing to have an 'adequate research based resource' and commented that despite advances over the previous decade the profession was 'Sadly...still some way from achieving this' (Kay, 1995 p96). More recent reports concerning learning disability nursing have acknowledged the importance of research. For example the Learning Disability Nursing Strategic Framework for Wales (Welsh Assembly Government, 2002) notes the need for nursing leaders to 'actively promote research projects that focus on clinical practice and clinical outcomes' and for them to support nurses to 'participate in clinical research and encourage nurses to seek opportunities to share and publish their findings through effective networking systems' (pages 10 – 11). Similarly a recent consultation document circulated by the United Kingdom Learning Disability Nurse Consultant Network (2005) has identified research as a key 'building block' of learning disability nursing alongside practice, education and leadership.

The development of learning disability nursing research is not solely dependent upon academic departments and the development of new roles such as the Nurse Consultant provides the opportunity for expansion in this area. Nonetheless Turnbull (1997) highlights the fact that, at the time he was writing, there were no senior academic posts in learning disability nursing in the UK. Leadership in this area was thus limited. Whilst this situation has improved somewhat over the past 8 years (with a number of learning disability nursing academics achieving promotion to senior/principal lecturer and reader posts, and chairs in learning disability existing/ being created in nursing departments) there is (to the authors' knowledge) still only one chair in learning disability *nursing* in the UK.

This literature review has highlighted some of the challenges facing learning disability nursing research and researchers wishing to develop research in this area. It has noted the perception that research in this area may be limited (Kay, 1995; Turnbull, 1997; Parahoo *et al*, 2002; Mitchell, 2004; Moulster and Turnbull, 2004) and it is important to acknowledge the danger that a lack of evidence of on the part of the profession may be interpreted as absence of a sound basis for nursing practice (Turnbull, 1997). Where research has been undertaken it is viewed as focussing primarily on staffing related, training and resource issues and rarely on clinical nursing practice (Kay, 1995). Nonetheless it is also important to note that, to date, no comprehensive review of the research undertaken by, or concerning learning disability nurses appears to have been published. The perception that research has been limited is, therefore, at present just a perception and without clear evidence

regarding the current situation it is impossible to identify strengths, weaknesses, trends and, most importantly, priorities for future development.

### **3. Aims and objectives**

The overall aim of this research was to undertake a review of the research published by, or concerning, learning disability nurses during the period 1995- 2003. It was undertaken in response to the rationale set out in the preceding literature review and its specific aims were to:

1. Identify research published by learning disability nurses, or concerning learning disability nursing practice, during the period 1995 – 2003
2. Determine the focus of the research and the methodologies/ methods used
3. Evaluate the quality of the research
4. Identify any evident trends (both in terms of subject areas and methodologies)
5. Identify gaps in the research and make recommendations for further work.

## **4. Study Design**

### **4.1 Method**

The chosen method for this study was a literature search followed by a literature review. According to Hart (1998) a literature review can:

- Assist in distinguishing between what has already been done and what needs to be done.
- Help to discover variables which are important and relevant to the chosen topic.
- Facilitate synthesis and assist in the development of a new perspective.
- Enhance acquisition of the subject vocabulary.
- Promote understanding of the subject structure.

Given the rationale set out in the background literature review (Section 2) this method is thus viewed as appropriate.

The project utilised a 5 stage search strategy that ensured that commonly used electronic databases were utilised and then supplemented by hand searching and snowballing in order to identify potential papers for inclusion. It was important to identify as many as possible of the papers that met the search criteria and also to be clear about the most effective search strategies by which to identify learning disability nursing research.

In stage 1 a search of 6 major and relevant electronic databases (CINAHL, BNI, Medline, ASSIA, Embase and PsychInfo) was conducted in order to identify the major nursing and learning disability journals that were indexed in each database.

In stage 2 the same databases were interrogated using the search terms learning (disability / disabilities / difficulties) mental retardation, developmental disabilities, intellectual disabilities and mental handicap combined with the word nursing or (separately) nurses. These terms were selected since they are those most commonly used to refer to the client group with whom learning disability nurses work. Where possible searches were limited to the period 1995-2003, to research articles, and to the English language.

In stage 3 the same databases were interrogated in order to undertake an author search of key authors in the field and authors emerging from the previous stages of the search. Stage 4 comprised a hand search of 21 key nursing, disability, and learning disability journals to identify papers not identified in previous stages. Finally the reference lists of papers obtained were reviewed in order to identify any further potential papers for inclusion. Stage 5 thus utilised a snowball technique.

### **4.2 Ethics**

All of the data gathered and analysed in this study was already in the public domain since the study involved secondary analysis of published data. Nonetheless the study was submitted to the School Ethics Committee of the School of Care Sciences, University of Glamorgan for approval. This was obtained before the research commenced.

### 4.3 Data analysis

To be included in the study papers had to meet the following criteria:

- Published between 1995 – 2003
- Focus on learning disability nursing and/ or written by learning disability nurses
- Report on research studies or upon the development of research methodologies
- Published in the English language

It was agreed that papers which comprised a scholarly review of the literature, but which did not include a systematic search strategy, would not be included in this review.

A proforma for recording the analysis of papers identified as meeting the criteria for inclusion was developed collaboratively by all three members of the research team. This was then tested for reliability and validity by all members of the team reading one qualitative and one quantitative paper. The results from individual analysis were then compared and some minor amendments made to the proforma. Also at this stage it was agreed to record the sample size as the number of people who participated in the study rather than the number invited to provide a clearer reflection of the actual size of the study. A copy of the proforma used is included in Appendix 1.

All papers meeting the inclusion criteria were then read by at least two members of the team and details entered onto the proforma. These were then compared and the details entered into Endnote and also into an Excel spreadsheet to assist with further analysis. Included papers were also entered into a category by subject and further analysis undertaken to seek to identify any key trends.

At this stage difficulties were identified with papers which did not originate from outside of the United Kingdom or Ireland. This was due to the fact that the ways in which nurses are trained to work with people with learning disabilities, and the ways in which they work, differ greatly in other countries. It was thus sometimes difficult to determine if an international paper should be included as it was not possible to make like for like comparisons such as whether a nurse author held a specialist qualification in the field of learning disabilities. For this reason it was agreed to include non UK or Irish papers if one or more of the authors held a nursing qualification *and* if the subject matter related to people with learning disabilities and/ or their families. However, it was agreed to analyse these papers separately from the main study and this is reflected in the presentation of results.

## 5. RESULTS

The results presented in this section are detailed against objectives 1-4 of the research listed in section 3 with an additional section for international papers which (for reasons outlined above) fell outside the scope of criteria but are nevertheless worthy of note both in the results and the discussion sections. Objective 5 is addressed in the discussion and conclusions sections.

### 5.1 Identification of research published by learning disability nurses, or concerning learning disability nursing practice

The first stage in the search strategy comprised the search of key databases to determine the extent to which relevant nursing, learning disability and disability journals were indexed with them. The results of this search are set out in Table 1 below.

Journal	CINAHL	BNI	Medline	ASSIA	Embase	PsychInfo
British Journal of Learning Disabilities	√	√	x	x	x	x
British Journal of Nursing	√	√	√	√	x	√
Journal of Learning Disabilities (previously the Journal of Learning Disabilities for Nursing, Health and Social Care)	√	x	x	x	√	x
Learning Disability Practice	√	√	x	x	x	x
Journal of Advanced Nursing	√	√	√	√	x	√
Nurse Education Today	√	√	√	x	x	x
Journal of Clinical Nursing	√	√	√	√	x	√
Journal of Psychiatric and Mental Health Nursing	√	√	√	x	x	x
Nursing Times	√	√	√	√	x	√
Nursing Standard	√	√	√	x	x	√
Nurse Education in Practice	√	√	x	x	x	x
Nursing Clinics of North America	√	√	√	x	x	√
Journal of Applied Research in Intellectual Disabilities	x	x	x	x	x	√
Journal of Intellectual Disability Research	√	x	√	√	√	√
American Journal on Mental Retardation	x	x	x	x	√	√
Health and Social Care in the Community	√	√	x	√	x	x
Disability and Society	√	x	√	√	x	√
Mental Retardation	x	√	√	x	√	√
NTRResearch	√	√	x	x	x	x
Mental Health Care	√	√	√	x	x	x
International History of Nursing Journal	√	√	√	x	x	x
International Journal of Nursing Studies	√	√	√	√	x	√
Nurse Researcher	√	√	√	x	x	x

**Table 1: Journals indexed with key databases**

Interrogation of the databases in stage 2 of the search (using the specified terms and, where possible, applying the specified limits) identified a range of potential papers for inclusion. These are set out in Table 2 below and further details of the searches undertaken with each term / database are included in Appendix 2. Different combinations of key words were found to produce differing numbers of hits.

	<b>Limit year?</b>	<b>Limit to research?</b>	<b>Limit to English language?</b>	<b>Total papers identified (after removal of duplicates)</b>
CINAHL	Yes	Yes	Yes	134
BNI	Yes	No	No	134
Medline	Yes	No	No	347
ASSIA	Yes	No	Yes	171
Embase	Yes	No	Yes	105
PsychInfo	Yes	No	Yes	230
<b>Papers warranting further review</b>				404

**Table 2: Results of key word search of databases**

The abstracts for these papers were reviewed and some were eliminated at this stage due to their not meeting the inclusion criteria. Common reasons for exclusion were papers published in languages other than English, papers which did not concern research, papers which focussed on other client groups (and were not written by specialist nurses) and abstracts which focused on unpublished research (such as PhD and Masters theses). 85 papers identified via the key word search of databases were deemed to meet the criteria for inclusion in the study. Of these 36 were identified by single, but differing, databases.

Stage 3 of the search comprised interrogation of the same databases using the author search facility. This identified a further 84 potential papers of which 29 were finally deemed to meet the criteria for inclusion in the study. Common reasons for exclusion here were duplicates from stage 2 of the search and papers by authors with initials and surnames similar to those of key learning disability nursing authors.

Stage 4 of the search comprised a hand search of key nursing, learning disability and disability journals. The results of the search are set out in Table 3 below. In total 32 papers were identified of which 26 were deemed to meet the inclusion criteria for the study.

<b>Journal</b>	<b>Number of papers not previously identified in Stages 2 or 3</b>
British Journal of Learning Disabilities	2
Journal of Learning Disabilities (previously Journal of Learning Disabilities for Nursing, Health and Social Care)	1
Learning Disability Practice	19
Journal of Advanced Nursing	0
Journal of Clinical Nursing	0
Nurse Education Today	0
Nurse Education in Practice	0
Health and Social Care in the Community	0
Journal of Intellectual Disability Research	0
Journal of Applied Research in Intellectual Disabilities	0
Disability and Society	0
NTRResearch	0
International History of Nursing Journal	0
International Journal of Nursing Studies	1
Nurse Researcher	0
American Journal on Mental Retardation	0
Mental Retardation	0
British Journal of Nursing	5
British Journal of Developmental Disabilities	2
Journal of Psychiatric and Mental Health Nursing	1
British Journal of Community Health Nursing	1
<b>Total</b>	<b>32</b>

**Table 3: Results of the hand search of key journals**

Only 2 further papers were added to the study during stage 5 of the search (snowball). These were both research reports from which published papers had been developed.

In total then 142 papers for inclusion in the study and further analysis were identified using the various search strategies (see Appendix 3 for full list of papers). Of these it was possible to determine that a learning disability nurse was an author in 129 instances.

## **5.2 The focus of the research and the methodologies/ methods used**

There are a number of key themes within the content of learning disability nursing research. We have been able to categorise these themes broadly into the areas of educational and professional developments; health care experiences; service

development and delivery; challenging behaviour; methodology; the role of the learning disability nurse; historical research; and therapeutic interventions (Table 4):

Theme	Brief outline	Number of papers
Educational and professional developments	Papers that relate to the education of students preparing to become learning disability nurses and those that relate to the education and professional development of practising nurses.	35
Health care experiences	Papers whose prime focus is concerned with the experiences that people with learning disabilities have when they come into contact with health care provision.	28
Service development and delivery	Papers that consider learning disability services together with some non specialist services that impact on the lives of people with learning disabilities.	23
Challenging behaviour	Papers that encompass a range of research about behaviour that challenges contemporary services.	18
Methodology	Papers that relate primarily to research methodology	15
Role of the learning disability nurse	Papers that explore the role of the learning disability nurse or that relate to debates specifically about learning disability nursing.	10
Historical research	Papers that concentrate on the historical development of learning disability nursing or about the history of learning disability.	7
Therapeutic interventions	Papers that are primarily concerned with interpersonal communication.	6

**Table 4: Themes evident in the research papers**

Table 5 below sets out the methodologies used within the studies / papers.

Qualitative	42
Quantitative	50
Mixed methods	25
Other (includes methodology, historical research and literature reviews)	25

**Table 5: Methodologies used in the studies**

Most of the qualitative studies did not explicitly state that they had used a particular methodological approach. However, of the 14 which did specify, 5 indicated that they had used grounded theory, 4 that they had used a phenomenological approach, 3 that they had used ethnography, 1 that they had used discourse analysis and 1 that a case study approach had been taken. The main method of data collection was unstructured or semi-structured interviews these being used in 35 of the 42 studies. However, use of focus groups (n=5), observation (n=5), diaries (n=1) and self-completion

questionnaires (n=1) were also evident. In some studies multiple methods of data collection were used.

One of the quantitative papers used a non-randomised experimental design and another used a quasi-experimental approach. Two further studies involved a single case study design. Within those studies using a quantitative approach (n=50) by far the most common method data collection method was the questionnaire with a survey approach being used in 33 (66%) of the papers. Some of these were postal surveys and others involved self-administered questionnaires. Other methods of data collection included interviews (n=6), secondary analysis of existing records (n=5) and use of rating tools / observation (n=5). In 7 studies some form of health assessment tool was also used. (It should be noted here that some studies used more than one method of data collection hence the total figure exceeds 50).

Within the 'other' category literature reviews were only included where the search strategy used was specified (unless they focussed upon discussion of research methodology). 3 papers used this approach. Six of the historical papers used documentary analysis of archival records.

The sample size within the quantitative studies ranged from 1 (a single case study design) to 1878. However, just over half of the studies (n= 26) had a sample size of less than 50, a further 12 had a sample of between 51 and 100, 7 had a sample of between 101 and 200, 4 had a sample of between 201 and 999, and only 1 study had a sample of over 1,000. Most studies were, therefore, relatively small scale.

### **5.3 The quality of the research**

In assessing the quality of the research a range of indicators needs to be considered. Analysis of individual papers will be included in the discussion section but here some other indicators of quality will be noted namely where papers are published, the use of key words in indexing papers, funding, and evidence of sustained lines of inquiry (sustainability).

Table 6 sets out where the papers included in the study were published (please note that total here is 140 since 2 of the studies included were in the form of published research reports rather than as journal articles).

Only 60 (42%) of the papers in the study included key words as part of the article. Within these key words a wide variety of terms was used.

Fourteen of the papers / reports indicated that they had received funding for the research. However, since in two instances two papers or reports relate to the same study, then this can be reduced to 12. Sources of funding included national nursing boards (n=6), health departments (n=3), independent sector care providers (n=2), and a health authority (n=1).

Journal	Number of papers
Journal of Learning Disabilities (previously Journal of Learning Disabilities for Nursing, Health and Social Care)	35
Learning Disability Practice	19
Journal of Advanced Nursing	11
British Journal of Nursing	11
Journal of Psychiatric and Mental Health Nursing	6
British Journal of Learning Disabilities	6
Journal of Clinical Nursing	6
Nurse Education Today	5
International History of Nursing Journal	4
International Journal of Nursing Studies	3
British Journal of Community Health Nursing	3
Health Bulletin	3
Nursing Standard	3
NT Research	3
British Journal of Developmental Disabilities	3
International Journal of Palliative Nursing	2
Nurse Researcher	2
Nursing Review	2
European Journal of Oncology Nursing	1
European Journal of Cancer Care	1
Health Services Management Research	1
International Journal of Language and Communication Disorders	1
Journal of Adult Protection	1
International Journal of Intellectual Disability Research	1
Journal of Nursing Management	1
Journal of Sexual Aggression	1
Mental Health Care	1
Narrative Inquiry	1
Nursing Inquiry	1
Primary Health Care	1
Social Sciences in Health	1

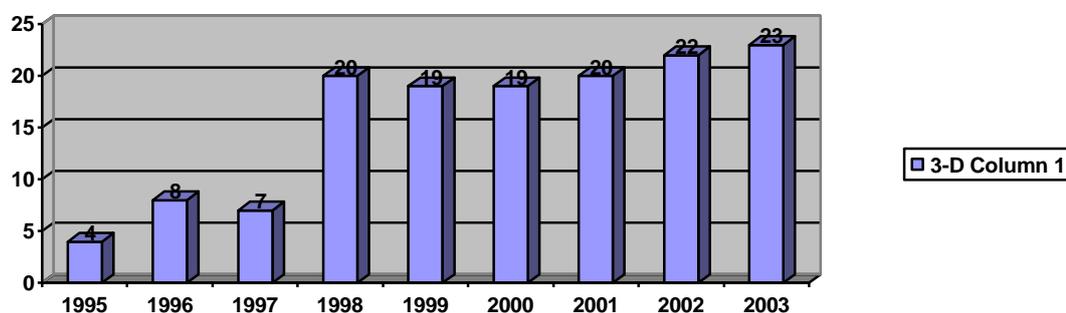
**Table 6: Journals in which papers are published**

Some evidence was found of sustained lines of inquiry both by individuals and by groups of researchers. In some instances these were methodological (for example Northway 1998, 2000, 2001; Richardson 1997, 2000, 2002) whilst in others they related to subject area (for example Bollard 1997, 1998, 1999, 2003; Mitchell 1996, 2000, 2001, 2002, and 2003). Examples of sustained lines of inquiry by academic departments included the work undertaken in the University of Ulster concerning health assessment and promotion (Barr *et al* 1999, Marshall *et al*, 2003, McConkey *et al*, 2002, Moore *et al*, 2003) and concerning attitudes (Bailey *et al*, 2001, Maggennis *et al*, 1999, McConkey *et al*, 2002, Parahoo *et al*, 2000, Slevin, 1995, Slevin and Since, 1996).

#### **5.4 Trends within the research**

After a growth in the number of published research papers written by learning disability nurses in 1998, the rate remained relatively steady for the rest of the period

under study (Figure 2). During the period of the research learning disability nurses published research papers in a total of 31 different journals (Table 6).



**Figure 2: Papers published by year of publication**

To identify any other possible trends, analysis was undertaken to compare journal (where 4 or more papers were published) with year of publication (Table 7), theme with year of publication (Table 8), journal with theme (Table 9) and methodology with year of publication (table 10).

	1995	1996	1997	1998	1999	2000	2001	2002	2003
Journal of Learning Disabilities			1	6	6	3	7	6	6
Learning Disability Practice				6	2	2	3	3	3
Journal of Advanced Nursing		1			1	6	1	1	1
British Journal of Nursing	1	2	1	1	1	1		3	1
Journal of Psychiatric and Mental Health Nursing	1	1	1	1					2
British Journal of Learning Disabilities			1			1	2	1	1
Journal of Clinical Nursing	2	1		1	1				1
Nurse Education Today					1			2	2
International History of Nursing Journal		1				1	1	1	

**Table 7: Papers in key journals by year of publication**

	1995	1996	1997	1998	1999	2000	2001	2002	2003
Educational and professional developments	2	2	2	6	5	5	4	5	4
Health care experiences	1		2	4	5	2	3	7	4
Service development and delivery		2	2	5	1	4	2	1	6
Challenging behaviour		1		3	3		5	2	4
Methodology	1	1	1	1	2	4	1	3	1
The role of the learning disability nurse		1		1		1	3	3	1
Historical research		1				1	1	2	2
Therapeutic intervention				1	2	2	1		

**Table 8: Theme of paper by year of publication**

	Educational and professional developments	Health care experiences	Service development and delivery	Challenging behaviour	Methodology	The role of the learning disability nurse	Historical research	Therapeutic interventions
Journal of Learning Disabilities	5	8	6	3	7	3	1	2
Learning Disability Practice	3	5	5	4	1			1
Journal of Advanced Nursing	3	5		1	1	1		
British Journal of Nursing	3	3	1	1	2	1		
Journal of Psychiatric and Mental Health Nursing	3		1	2				
British Journal of Learning Disabilities		1	2	1		2		
Journal of Clinical Nursing	1	1		1	1	2		
Nurse Education Today	4						1	
International History of Nursing Journal							4	
International Journal of Nursing Studies		1	1	1				
British Journal of Community Health Nursing	1	1				1		
Health Bulletin		1	1	1				
Nursing Standard	1		1	1				
Nursing Times Research	1		1				1	
British Journal of Developmental Disabilities	1			1				1
International Journal of Palliative Nursing	1	1						
Nurse Researcher					2			
Nursing Review	1							1

**Table 9: Papers published in journals by theme (2 or more papers published in journal)**

	1995	1996	1997	1998	1999	2000	2001	2002	2003
Qualitative	2		2	10	6	5	2	8	7
Quantitative	1	2	3	6	9	7	11	4	7
Mixed methods		4	1	3	2	2	5	5	3
Other	1	2	1	1	2	5	2	5	6

**Table 10: Methodology by year of publication**

## 5.5 International Papers

A comparison with international research is difficult because of the lack of cross cultural terms and a difference in the work that nurses, and other professionals undertake. For example the American term ‘developmental disabilities’ is not generally used in the United Kingdom and the term ‘learning disabilities’ which is widely used in the United Kingdom indicates dyslexia in some other countries. In terms of the work that professionals undertake there is little international commonality between the work of various specialist learning disability nurses.

As previously noted the decision was taken to separate out those papers which did not originate from either the United Kingdom or Ireland from those which form the main part of this study. The reason for this was that the specialism of learning disability nursing does not exist in the same form in other countries. Hence it was often difficult to determine whether papers had been written by or about specialist nurses and there was the danger of not comparing like with like. Nonetheless, it was felt important to acknowledge the existence of international studies which may have relevance.

Studies were thus included in this section if one or more authors held a nursing qualification *and* if the subject matter of the research was related to people with learning disabilities and/ or their families. On this basis 14 papers were identified from the search strategy previously outlined (see Appendix 4). These papers originated from the United States (n=8), from Australia (n=3), from Hong Kong (n=2) and from the Netherlands (n=1). The range of journals in which they are published, and their years of publication, are set out in Tables 11 and 12 below.

Name of Journal	Number of Papers
Public Health Nursing Journal	1
Pediatric Nursing	1
American Journal of Mental Retardation	1
Issues in Mental Health Nursing	1
Journal of School Nursing	1
Australian and New Zealand Journal of Mental Health Nursing	1
Australian Journal of Advanced Nursing	1
British Journal of Developmental Disabilities	1
Scandinavian Journal of Caring Science	1
Journal of Pediatric Nursing	2
Journal of Clinical Nursing	1
Clinical Nursing Research	1
Mental Retardation	1

**Table 11: Journals in which international papers have been published**

<b>Year of Publication</b>	<b>Number of Papers</b>
1995	1
1996	4
1997	-
1998	2
1999	-
2000	2
2001	1
2002	2
2003	2

**Table 12: Year of publication of international papers**

The methodologies used within the research studies reported in these papers varied and included quantitative (n=8), qualitative (n=3) and mixed (n=3). Sample size within the quantitative and mixed methodology studies ranged from 27 to 523. The subject areas addressed also varied and these are set out in Table 12 below.

<b>Subject of Research</b>	<b>Number of Papers</b>
Family care	7
Nursing care	3
Experience of health care	2
Educational and professional development	1
Service development and delivery	1

**Table 13: International papers by theme**

## 6. DISCUSSION

The findings of this study will be discussed in relation to the objectives of the research. Within this section discussion of the international papers identified in the search will be integrated with discussion of the UK and Irish papers so that comparisons can be made where possible.

### 6.1 Research published by learning disability nurses, or concerning learning disability nursing practice

The first stage of the search involved examination of the databases to identify which of the key journals were indexed with which database. It was found that of the databases interrogated no single database indexed all of the key journals. The use of Embase and PsychInfo were found to be necessary to access the American Journal on Mental Retardation, a key journal within the US. Whilst CINHAL and BNI were found to be the most comprehensive in terms of journals indexed the number of papers identified in this study via the use of a single database (n=36) suggests that the use of multiple databases is required particularly if some of the international research is to be accessed.

When searching the databases using the key words it was not possible to apply limits to the search in all instances. This resulted in the identification of a number of papers which were not research based. The use of differing terms produced different results and this was evident in two key respects. First the use of the term 'nursing' produced different results from use of the term 'nurse' and in most instances the term 'nursing' tended to produce more. Second the use of different terms to refer to the client groups (for example learning disability, developmental disability, intellectual disability) also produced differing results and, in some instances, this also applied to use of the term 'disability' as opposed to 'disabilities'. This suggests that it is necessary to use differing combinations of terms and, where possible, to use the facility which allows for use of truncated terms.

Nonetheless it should also be noted that terms can have different meanings in different countries. A prime example of this is the term 'learning disability' which in the US refers to those who have dyslexia. Hence a search using this term in combination with 'nursing' produced some papers which focussed on the needs of nursing students who have dyslexia.

The initial search of the databases using key words produced 404 papers which warranted further examination but only 85 of these were finally included in the study. A common reason for exclusion at this stage was that when a paper was reviewed it was evident that it was either a discussion piece or a scholarly review of the literature rather than research or a systematic review of the literature which included the search strategy. If authors had included such a search strategy then the number of papers included would have been greatly increased but, more importantly, this would have been a key contribution to the development of the theory base within learning disability nursing from which further research could be undertaken.

The databases were interrogated using the author search facility. However, whilst this did result in the identification of a further 29 papers for the study it also proved to be

problematic. Some learning disability nursing authors were found to have surnames and initials identical to other authors and, since learning disability nurses do research in other areas, it was sometimes difficult to identify whether the paper could be included or not. In addition whilst the author names to be searched were identified via the previous stage of the study, it was not possible to identify in all instances whether an author held an RNLD qualification and hence whether they should be followed up at this stage.

The hand search of journals resulted in the identification of a further 32 papers for inclusion. It is interesting to note here that all of the papers included in the study from Learning Disability Practice were identified via this method. This may be due to the fact that this journal has only been more recently indexed with the databases and the use of key words to accompany articles was not introduced in the journal until 2004.

These difficulties with identifying relevant papers would appear to support the findings of the study undertaken by Parahoo *et al* (2000) in which respondents cited a lack of access to research information as a reason for its lack of use within learning disability nursing.

The overall number of papers included at 142 is not large given that this study covers a 9 year period. It should also be noted that this does not refer to 142 different studies since some papers relate to research methodology and some present different aspects of the same study.

As with the papers identified in the wider study a number of international papers identified were excluded due to their being primarily scholarly reviews of literature rather than primary research or literature reviews which had been undertaken in a systematic manner. The papers included were published in a wide range of journals and hence it is not possible to identify just one or two journals which potential readers could regularly review to access the international nursing literature concerning people with learning disabilities. In addition it is interesting to note that the majority of papers are published in nursing journals and none are in international learning disability journals such as the *Journal of Intellectual Disability Research*. However, 1 paper is published in the *American Journal of Mental Retardation* and another in *Mental Retardation*. Both of the journals from the US are widely accessed by an international audience.

As noted above it was, in some instances, difficult to identify whether authors held the RNLD qualification or not since not all journals list author qualifications. However, web searches and personal contact with some authors meant that it was possible to identify that in 129 of the 142 papers included at least one of the authors was an RNLD. The majority of published learning disability nursing research would thus appear to involve learning disability nurses.

## **6.2 The focus of the research, the methodologies and methods used**

### **6.2.1 The focus of the research**

It was difficult to assign papers to a single category since, in some instances, a single paper could touch upon more than one theme. For this reason papers were assigned

according to the dominant theme as identified in Table 4. The largest number of papers was assigned to the theme of educational and professional developments. Perhaps this is not surprising given that a common recommendation from the studies reviewed was that more education and training needs to be provided for both learning disability and non learning disability staff. Nonetheless it does support the observation by Kay (1995) that learning disability nursing research tends to focus upon staffing related training and resource issues rather than upon clinical nursing practice particularly if this theme is considered in conjunction with that of service development and delivery which included a further 23 papers. The second largest grouping of papers (n=28) related to the experience of health care and this is perhaps a reflection of an increased emphasis on this aspect of the role of the RNLD over the past decade. The sections below provide a review of the studies included in each of the themes highlighting both the key findings and, some strengths and weaknesses of the research reviewed.

#### *6.2.1.1 Educational and professional developments*

Thirty five of the published papers in the review were concerned with educational and professional developmental issues in learning disability nursing. Some considered the educational process itself and most of these concerned pre registration nurse education. Others were concerned with specific needs of qualified nurses and because of the nature of the subjects some of these are considered within other themes. During the period of the research most of the pre registration educational programmes in learning disability nursing were organised within the framework of Project 2000 (UKCC, 1986). A small number of joint programmes in nursing and social work were also in progress. The English National Board for Nursing Midwifery and Health Visiting commissioned a primary research project that was published in 2001 (Alaszewski *et al* 2001). This found that that the skills of learning disability nurses were valued by users of services and other professionals and that their role could be expanded. However they also recommended that users of services should be better used in educational programmes and should become active partners. This recommendation reflects a trend within learning disability nurse education but there was little reflection of this within the research, Fisher and Coyle (1999) being an exception to this in that they conducted a small scale survey among nurse educationalist in Wales into service user involvement in nurse education. The study found that despite the fact that the service user perspective had become increasingly important there was very little user involvement in learning disability nurse education in Wales. Manthorpe *et al* (2003) confirmed that there is little firm evidence for the involvement of users in pre registration education. They suggest that this does not necessarily mean that such involvement does not exist but that it is not highlighted in published work, or even in education programme materials.

Norman (1998 a & b) published two papers that reported the findings of a project commissioned by the ENB into the changing educational needs of mental health and learning disability nurses. The study involved interviews with 88 mental health and 59 learning disability nurses. It is at times difficult to disentangle the separate needs of each group but he suggested two difficulties for nurse education. He found that there were several models of nurse education and that nurses tended to have a strong allegiance to one or more of the models thereby presenting a disunited front. This

made it difficult for educational providers to develop a coherent educational structure (Norman 1998a). He also argued that it was difficult for educators to strike a balance between meeting the needs of service providers and maintaining standards of scholarship demanded by higher education (Norman 1998a).

Interestingly, given that the joint programmes in nursing and social work were the culmination in many years of discussions between the GNC and CCETSW following the Jay Report (DoHSS, 1979), there was little published research on these programmes in the period under study. The three papers that were included were broadly supportive of the initiative although Etchells *et al* (1999) drew attention to the role conflict experienced by many students. Simms (1999) in a small survey of nurses / social workers who had graduated from the South Bank joint programme found that although they were frustrated about the lack of joint posts available to them were nonetheless able to promote holistic practice and work in an inter-professional way within their uni-professional posts. Kwiateck and McKenzie (2002) in a quantitative study of the views of managers found that most professionals, despite significant reservations felt that dual qualification training was a positive move. McCray and Carter (2002) in a study that tried to identify the needs of a future learning disability practitioner confirmed that the skills of both social work and nursing were required. The conclusion was that it is the ideal time for 'the promise of jointly qualified professionals to come to fruition'. However Norman (1998a) found that although there was widespread support among mental health and learning disability nurses for multi-professional education there was less enthusiasm for joint training as nurses were seeking a role that was collaborative but distinct from other professions.

Other studies considered the processes within pre registration nurse education. Davies *et al* (2002) for example, evaluated the experiences of student nurses involved as researchers in a mental health project. The evaluation confirmed that involving students in research projects was a successful way of promoting learning about the research process. Marsland (2001) considered student nurses use of career guidance and found that there was little take up of the facilities available.

Attention was given to the educational role of the nurse in a number of studies. Typically this involved working with other professionals to help them to understand the needs of people with learning disabilities. This was restricted to two groups of professionals: general nurses and the police. In addition there was also attention given to the needs of learning disability nurses themselves. The research carried out on the police was based in Northern Ireland and included two accounts of training of police officers, one jointly with social workers (McAllister *et al*, 2002) and one that reported on awareness training and police attitudes to people with learning disabilities (Bailey *et al*, 2001). This research was preceded by a paper by Bailey and Barr (2000) that investigated police policies on the investigation of sexual crimes committed against adults with learning disabilities. Bailey and Barr demonstrated that there was variation across England, Wales and Northern Ireland in police policies concerning crimes committed against people with learning disabilities.

Five studies within this theme investigated staff working in acute hospitals and primary care; they are included within this theme because they are significantly about staff working in these fields rather than experiences of people with learning disabilities themselves. Combined with the articles that we have grouped within the

health care experiences theme this makes the issue of health care a significant subject in the research. Findings were consistent in that health care staff lacked knowledge and confidence in working with people with learning disabilities. For example Courell (1997) found that nursing staff had difficulties and concerns about their ability to communicate with people with learning disabilities; and Lindop and Read (2000) reported that district nurses require greater specialist knowledge and skill in relation to caring for people with learning disabilities especially in the area of communication. Slevin's (1995) research on nursing students was encouraging in that he found that students who experienced the Project 2000 education that included learning disability placements had significantly more positive attitudes to people with learning disabilities than those who had not had such a placement. Unfortunately, however, subsequent changes in pre registration nurse education have led to a number of schools of nursing discontinuing such placements and hence this is an area where current research may be required in order to assess the impact of such changes.

A number of studies pointed to the lack of expertise of learning disability professionals in specific areas. Casey and Barr (1995) for example, in a small study involving 8 professionals suggested that there was a lack of understanding of mental health problems experienced by people with learning disabilities. Culley and Genders (1999) in a survey of 266 practitioners found that community nurses did not feel adequately prepared by either pre or post registration training to support the needs of parents with learning disabilities. Parahoo *et al* (2000) considered the extent to which learning disability nurses used research within their practice. Having questioned 87 learning disability nurses from three hospitals they found that a large minority (18.3%) reported that they believed that research was not relevant to their day to day practice. However, one quarter reported that they were using research frequently in their practice and there were some generally positive attitudes to research.

Other papers were concerned with the educational and development needs of learning disability nurses themselves. These papers tended to relate to specific areas of work, their general application being that education and development is worthwhile and needs to continue throughout individual careers. This relates to the places in which people work as well to their function. Smith and Chung (1996) for example, in a survey of staff working in both residential and hospital settings, reported apprehension about community work. Riding (1996) found that awareness training among nurses at Ashworth hospital had a positive effect on the way in which participants regarded service users. Ng and Li (2003) conducted a survey of learning disability care practitioners to assess their awareness of issues related to death and dying. Many of the respondents, all of them singly or doubly qualified nurses, had a lack of knowledge of specialist care for people in terminal illness, had poor communication skills and limited knowledge of the signs and symptoms of the late terminal stage of life. Ng and Li recommend that the issue of death and dying be given much greater prominence in pre registration education. Parahoo *et al* (2000) suggested that learning disability nurses require an educational programme to further encourage their use of research. McIntosh (1998) explored how 3 community learning disability nurses coped with the chronic grief often expressed by the families with whom they work. He found that dealing with such emotions reminded the nurses of their own loss in relation to familiar work roles and structures recommending that such issues be addressed within supervision. On a positive note, and in a small study,

Malin (2000) found that clinical supervision was helpful to learning disability nurses and resulted in improved teamwork and reflective care.

There were some papers that were written by learning disability nurses and were about education and development but did not specifically address learning disability nursing. These came within our criteria because of the status of at least one of the authors and are loosely related to this theme. Maggennis *et al* (1999) for example makes recommendations about the support systems necessary for extended and expanded clinical roles of nurses working in acute general hospitals. Mansell *et al* (2002) carried out an all Wales survey of lecturers in nursing and found that student nurses required a large amount of support in preparing for written assignments. O'Callaghan and Slevin (2003) investigated the experiences of nurses facilitating supernumerary nursing students in Ireland. Slevin and Sines (1996) carried out a survey of the attitudes of general nurses in acute hospitals and discovered negative attitudes towards people with learning disabilities.

#### 6.2.1.2 Health care experiences

In total 28 papers were allocated to this category although, as with other categories, some papers might also be considered to reflect certain aspects of other categories. In such instances the decision to allocate them to this particular category was taken on the basis that the prime focus of the paper is concerned with the experiences which people with learning disabilities have, or might be expected to have, when they come into contact with health care provision.

The largest group of papers to be included in this category (n=10) relate to various aspects of assessing the health needs of people with learning disabilities. One paper (Mathews and Hegarty, 1997) is concerned specifically with the development and testing of reliability and validity of the OK Health Check, a widely used health assessment tool. This multi stage research study identified items for inclusion in the checklist via the use of the Delphi technique and then subsequently tested the resultant tool for reliability and validity with both qualified and unqualified staff. The paper concludes that the tool can be used by both qualified and unqualified staff to identify health problems which might not otherwise have been revealed. Other papers (Paxton and Taylor, 1998; Barr *et al*, 1999; Bollard, 1999; Martin, 2003) are concerned with the provision of health screening for people with learning disabilities and may be seen as a response to earlier papers (for example Howells, 1986; Wilson and Haire, 1990) which identified that when such screening is offered to people with learning disabilities then previously unidentified (and hence untreated) health problems could be recognised. The sample sizes in these more recent studies range from 65 (Bollard, 1999) to 373 (Barr *et al*, 1999), they use different approaches to physical assessment, and some use additional approaches to data collection. Due to these differences in methods and data collection tools it is not possible to make direct comparisons. Nonetheless all identified previously unidentified health problems. Only one paper (Martin, 2003) attempted to take a longitudinal approach and of the 71 people who attended for a health check at some point during the five-year study period only 16 attended each year. This highlights the difficulties with attrition within longitudinal research.

Health assessment should, however, not be an end in itself – action is required to address any health problems which are identified. Two papers from Northern Ireland (McConkey *et al*, 2002 and Marshall *et al*, 2003) thus seek to address this issue. GPs would appear to be key to addressing the health needs of people with learning disabilities and thus McConkey *et al* surveyed GPs who had been sent information concerning the health screening initiative and who had received a referral following a visit by one of their patients to the health screening project. They concluded that the project proved valuable both in highlighting unmet health needs and also in bringing about an apparent change in GP attitudes which provided a basis for developing new ways of working. The paper by Marshall *et al* provided an intervention for 20 clients who had been identified via health screening as needing to lose weight. The intervention led to a significant reduction in both body weight and BMI over a six week period in those needing to lose weight. They conclude that health screening per se has limited effect on reducing weight amongst the client group and that health professionals need to work in partnership with people with learning disabilities and their carers to promote and create more active lifestyles.

The final papers relating to assessment of health needs are concerned with health screening for adults with Down Syndrome aged over 30 (Paxton *et al*, 2001), the ways in which learning disability nurses assess and understand pain in clients who have no verbal communication (Donovan, 2002), and the assessment of health needs in one client with severe learning disabilities (Callan *et al*, 1995). This latter paper is interesting in that it uses a grounded theory approach to facilitate the development of a better understanding of the health needs of one man with severe learning disabilities amongst a staff team. It thus differs from other studies in that it uses a qualitative approach rather than the more usual quantitative approach to health assessment and also it links a research approach (grounded theory) very closely to practice development. It acknowledges that the results are not generalisable (and indeed should not be so since the aim is to gain a better understanding of individual circumstances). Nonetheless, it is possible to generalise the methodology and this may offer an alternative approach to health assessment. No other (later) papers using this approach were, however, identified in the current study. The paper by Donovan takes a phenomenological approach to explore the experience of learning disability nurses who have been with clients who may be in pain. Five key themes emerged namely the importance of a caring relationship with the client, recognising changes in verbal and non verbal behaviour, searching for a meaning in the client's behaviour, negotiating with other health professionals and sharing in the client's feelings.

The next group of papers (n=6) relate to varying aspects of service development concerned with health promotion. The first (Hebron, 1999) is an evaluation of patient held health records for people with learning disabilities. Information was sought via questionnaires administered to service providers at the beginning and end of the trial period. It is concluded that that such records may show potential both in relation to facilitating more active involvement of people with learning disabilities in their health care and also in promoting better collaboration between service providers. It is acknowledged, however, that it is a small scale study (98 service providers relating to 26 clients) and that further research is needed.

Two studies (Marshall and Foster, 2002 and Moore *et al*, 2003) are concerned with the provision of school nursing services to children attending special schools. Both

studies identify a range of roles undertaken by school nurses in such settings and Moore *et al* suggest that the role will vary according to the needs of children attending a specific school. A common policy is not, therefore, deemed appropriate. In both studies the authors note limitations due to the small sample size (Moore *et al*, 2003) and lack of a control group (Marshall and Foster, 2002).

The other studies in this group relate specifically to the dental and oral health needs of people with learning disabilities (Rawlinson, 2001), dietary and bowel management (Dickson *et al*, 2002), and the provision of services for people with epilepsy (Codling, 2001). In each instance some deficits in service provision were identified although satisfaction with current provision was also noted in relation to both dental and epilepsy services.

One area of concern in relation to the provision of health care for people with learning disabilities relates to the issues of capacity and consent and two of the papers (Hart, 1999 and Broughton, 2002) focus on this particular area. Hart's small scale qualitative study of 13 adults with learning disabilities revealed that approaches to consent varied widely and included examples of someone who required support being deemed competent whilst another, who was competent, was not asked to give consent which was obtained instead from her mother. Hart concludes that despite legal and professional guidance the situation in relation to consent is 'haphazard' and she recommends that consent should be viewed as a process which assists people with learning disabilities to gain a better understanding of their treatment and its implications. The paper by Broughton is concerned with the specific area of capacity and consent in relation to the cervical smear test and is not a primary research study. Instead it is a literature review which has been conducted in a systematic manner and hence its inclusion in this study. The paper concludes that cervical screening should be actively promoted to women with learning disabilities and their carers and that appropriate education, knowledge and support should be provided to assist women with learning disabilities to make informed decisions concerning screening.

This category of papers was given the title of 'Health Care Experiences' for the reason outlined at the beginning of this section. Nonetheless, thus far, the papers reviewed have not explicitly focused on the experience of services (although some sought such views concerning this alongside other data). Three papers did, however, specifically seek to gain a better understanding of how health care provision is experienced. The first of these (Stanley and Ng, 1998) is concerned with parental views concerning accessibility and experience of using primary care services for people with learning disabilities. The survey of 34 parents identified that families look to GPs as the key to health care provision for their sons and daughters with learning disabilities but also revealed concerns that primary care is not working sufficiently well for people with learning disabilities. It is recommended that greater coordination between services is needed and also that specialist learning disability professionals (including community learning disability nurses) should link more closely with primary care provision.

The other two papers concerned directly with experiences of health care seek to access the views of people with learning disabilities themselves. Hart (1998) used a qualitative approach to discuss with 13 people with learning disabilities their experiences of using general hospitals. A number of problem areas were identified

such as fear, the experience of nursing care, communication difficulties, and the need for treatment. Whilst it is acknowledged that these problems may affect anyone using hospital provision people with learning disabilities are likely to be 'disproportionately' affected. The need for further research is identified. Broughton and Thomson (2000) used a mixed methods approach to examine risk behaviours and experiences of cervical screening. 52 women with learning disabilities and 34 carers were interviewed. It was found that of those women who had had the test most had experienced pain and difficulty. However, a number of enabling factors were also identified which included prolonged preparation, issues surrounding communication, giving information and support from carers. Limitations were noted by the authors due to the exclusion of women with severe learning disabilities from the research.

The next group of papers (n=4) relate to the knowledge and attitudes of health care professionals which may influence the experience of health care by people with learning disabilities. The first (Bollard, 1997) involved a survey of 50 GPs and sought to determine their understanding of the specific health care needs of people with learning disabilities and their awareness of services which may assist in meeting such needs. The findings revealed a lack of awareness of local service provision, a lack of understanding of the role of the community learning disability nurse and only limited knowledge of the specific health needs of the client group. Stanley (1998) also surveyed GPs (n=88) to ascertain their views concerning the delivery of primary health care services to people with learning disabilities. Half of the GPs felt that the lead responsibility for primary care for people with learning disabilities did not lie with them. However, whilst 27.3% felt that there was a need for more specialist input slightly over half felt that they would like more hands on experience. It is recommended that consideration needs to be given as to how best to train GPs to work with people with learning disabilities.

Jenkins and Harris (1999) surveyed both hospital and community based registered learning disability nurses (n=112) to determine their perceptions concerning the use of psychotropic medication for people with learning disabilities. The nurses were found to be more united than divided on many of the key issues but there were key differences between hospital and community based staff in relation to the types of behaviours most likely to lead to the prescription of psychotropic medication. The final paper in this subsection (McKenzie *et al*, 2002) sought to determine the knowledge of two social care staff groups concerning dementia. In total 87 were surveyed of whom 50 supported someone with Down Syndrome and 37 did not. It was found that those who supported someone with Down Syndrome could identify significantly more health problems than those who did not and a higher proportion of the former group reported that they knew what Alzheimer's Disease is but the difference was not significant. Few staff in either group were able to identify signs and symptoms which can mimic dementia in people with Down Syndrome. It is concluded that training should be provided for staff supporting clients with Down Syndrome and that further research is needed to evaluate the impact of training packages.

One paper which does not fit readily into another category but which is concerned with a health issue experienced by people with learning disabilities is that by Doyle and Mitchell (2003). This is a review of the literature concerning post traumatic stress disorder and people with learning disabilities. It is conducted in a systematic manner

and highlights that there is limited literature concerning this subject and what literature there is, is not used in the work concerning the health needs of people with learning disabilities. It is suggested that trauma may manifest itself as changes in behaviour which are misdiagnosed and treated as challenging behaviour. It is recommended that further examination of this issue is required both in relation to diagnosis and treatment.

The final two papers in this section (Dunniece and Slevin 2000 and 2002) do not relate specifically to people with learning disabilities. They are included as one of the authors (Slevin) is a learning disability nurse. Nonetheless, since they relate to nurses experiences of being with patients receiving a diagnosis of cancer and to the knowledge of palliative care nurses, they do have relevance given increased awareness of the impact of cancer on people with learning disabilities. It is concluded that multi disciplinary planning is needed to improve the way in which bad news is given to patients and that further research is needed to expand the knowledge base of palliative nursing.

### *6.2.1.3 Service development and delivery*

Twenty three papers were judged to be within the theme of service development and delivery. This theme considered the research written about learning disability services and their development. It included investigations into the nature of learning disability teams as well as a range of separate, mainly small-scale studies of local issues in learning disability services. The most common method of enquiry was interview or questionnaire to discover the views, or perceptions of people about learning disability services. Most of the research was conducted with people working in services, or with carers, with only a small amount of attention being given directly to the views of people with learning disabilities.

The investigations into the nature of learning disability teams concentrated on describing the nature of the teams as well as trying to understand the roles of different members of teams. Aylott and Toocarum in one of the few investigations of the views of people with learning disabilities investigated both users and carers of services about the extent to which community teams met their needs. Whilst broadly satisfied with what was offered both groups requested a number of additional services. Interestingly there was a difference between the two groups in that carers tended to ask for more practical services and people with learning disabilities asked for more occupation, leisure and employment opportunities.

It appears that there is no consistency within the composition of community teams across the country. McKenzie *et al* (2000) for example surveyed teams across Scotland and found that while nursing, psychology and speech therapy featured in all teams, other professions had no input into some of the teams. Knowledge about community learning disability teams among other primary care professionals is also lacking as demonstrated by Carlson *et al* (2003). The issue of services at the transition between child and adulthood was examined by Carlson *et al* (2003) who asked parents with experiences of either lifespan or separate child and adult learning disability services about their views. The results were inconclusive but the researchers argues that service planners need to identify ways in which practitioners can develop

specialist skills as well as provide a service across the transition from child to adult. There was a small amount of evidence within the research examined to suggest that families were concerned about the nature of the support that they received rather than the specific role of the professional. Summers and Jenkins (2001) considered the views of families supported by portage workers or other professionals within the community team and found that there was no difference in either the support or in the outcomes for their children between different groups of professionals.

Some attention was given to the ways in which people work within a multi professional environment. Dobson *et al* (1998 and 2000) reported on an action research project that sought to improve the quality of the communication environment in a small disciplinary teams working in a special care unit. They found that success was more likely, both with team members and visitors when the approach to communication was systematic and carried out by all members of staff. Bradley (1998) researched the views of 5 community learning disability nurses, 5 day care officers and 5 informal carers about their perceptions of need of people with learning disabilities. He found that there was a lack of objectivity in defining need and considerable differences between the three groups. Parley (2001) in asking whether desired outcomes were improved within a person centred care model found that the lack of multi professional involvement (Parley predominately studied person centred care within nursing environments) was a barrier to person centred care. However, a positive finding by Tait *et al* (2002) was that co-ordinated services for children with complex needs work well and benefit both parents and professionals.

Two papers looked at respite care for people with learning disabilities finding that that there were variations in the services available that often failed to meet the needs of users (Sines 1999 and Hickson and Poole 1998).

Three papers consider learning disability services using clear methodological frameworks developed within the social sciences. Small *et al* (2003) compare the lives of young people with learning disabilities to recent sociological work on young people generally. Following a case study approach they argue that new models of choice over emphasise the individual and neglect the social context within which people with learning disabilities in particular live their lives. This risks further marginalising people with learning disabilities from both sociological discussion and the resulting policy implications. Gilbert demonstrates the value of investigating discourse within services to come to an understanding of power. Gilbert (2003) and Gilbert *et al* (2003) suggest that discourse with learning disability services promotes one particular version of the truth to the exclusion of other versions. Care planning is examined though a Foucauldian perspective to suggest that the supported living model is effectively promoted to the exclusion of other models of care. Gilbert makes reference to normalisation as one of the guiding philosophies within learning disability services but interestingly it is not a major theme within the research that this review has examined. One of the exceptions to this is an ethnographic study by Riding (1997) that suggested that normalisation is widely misinterpreted and misunderstood.

Alderwicke *et al* (1998) also investigated the organisation of learning disability services in the context of reorganisation into NHS Trusts. They surveyed heads of nursing, psychology and occupational therapy in 41 Trusts and received a 61%

response rate (n=60). The majority of respondents believed that specialist learning disability Trusts currently provided the best quality care for people with learning disabilities and that they were the preferred model for the future.

Cash *et al* (2000) used the Personal Outcomes Measures tool to examine the extent to which services were person centred. A multi-agency approach was taken and 35 interviews were undertaken with service users or those who knew them well. Of the possible 25 outcomes typically only a third were present in people's lives and those living in large settings were less likely to achieve outcomes they personally defined as important than those who living at home, independently, or in small group settings. The need to identify personally desired outcomes and to bring about incremental change is recommended.

Other studies were more difficult to categorise. Bailey and Barr (2000) for example reported on a project that was designed to collect preliminary information into police policies for investigating sexual crimes against people with learning disabilities. This was part of a wider study that also features in the educational and professional development theme. Bailey and Barr found that there was little consistency in the policies of the police across England and Wales concerning the investigation of abuse against people with learning disabilities. The majority of police forces had no clear policies. Slevin *et al* (1998) interviewed service providers to discover the barriers to independent travel among people with learning disabilities. They found that, although independent travel was viewed as a valuable skill, there were relatively few people with learning disabilities who practice it, the most significant obstacles being the cognitive abilities of people with learning disabilities and the wishes of carers. Slevin *et al* (1996) discussed a quality initiative that used a redesigned needs and strengths nursing assessment that improved both quality of life for people with learning disabilities and staff morale. Robinson *et al* (1997) studied quality of life measures within a high security environment and found that the application of a subjective quality of life tool revealed areas of life among people within the secure environment were not being monitored. In particular they found that issues of stress, shame and loneliness were being experienced but not noticed by staff within the unit. McNally (2003) found that there were a plethora of different models of self-advocacy groups in existence and that they defied a rigid prescription of what was ideal. In examining the position of non-disabled advisors to groups he found that it was their characters rather than status within organisations that was key to their effectiveness.

#### *6.2.1.4 Challenging behaviour*

This theme of published literature encompasses a range of research about behaviour that challenges contemporary services. There were a total of 18 papers in this broad theme, 13 of which were quantitative, 4 qualitative and 1 mixed methods. Sample sizes were mostly small but ranged from 3 to 185. Attention was divided between evaluations of methods of dealing with challenging behaviour and staff attitudes, knowledge and awareness of challenging behaviour issues. Some papers combined both of these features as they evaluated staff training and development. For example Edwards (1999a) found that staff reported significantly changed, and improved, behaviour on their own part after training that concentrated on teamwork skills. The nature of staff training in dealing with challenging behaviour was also examined by Kaye and Allen (2002) who suggested that a more sophisticated approach to training

was required to avoid unnecessary training in techniques that were unlikely to have been used. Murray *et al* (2001) suggested that staff were able to be flexible in the way that they worked if they were properly consulted about changes. Their research involved an exercise in which nursing staff who worked in an inpatient treatment and assessment unit for people with challenging behaviour were asked their views about trying to reduce the number of admissions by doing more within community settings. Whilst staff were generally positive about the proposals the researchers felt that they could clearly demonstrate areas for further staff training. The need for staff to be able to deal with challenging behaviour is highlighted by the finding of research carried out in Scotland by McKenzie *et al* (1999) that 63% of child referrals and 60% of adult referrals to a learning disability nursing service were identified as involving challenging behaviour. There is also evidence to suggest that people with learning disabilities who have difficulty to manage behaviour are being inappropriately placed. Woods and Mason (1998) examined data from the case register of a special hospital over a twenty year period (1975-1994) and found that people with mental impairment were more likely to be admitted for non-serious offences than those without mental impairment. Woods and Mason suggested that there was a need for more long term medium to low secure facilities to avoid inappropriate admission to special hospitals.

Evaluations of methods of managing challenging behaviour included a study by Sawuck and Reeves (2003) that investigated the use of an adapted survey instrument called the checklist of challenging behaviour. The study examined 35 returned checklists completed by both qualified nurses and unqualified care staff working on a secure unit. The results revealed that there were frequent episodes of challenging behaviour that were regarded as low risk and low frequency behaviours that were of higher risk. It was the latter that were rated higher in terms of management difficulty. Recommendations included the view that training should cover both types of challenging behaviour. Burns *et al* (2003) used a single case study design to describe an anger management programme. The programme was designed and implemented for forensic in patients with challenging behaviour. Evaluation of the programme showed that it was useful but that maintenance treatment was required to ensure long-term success. Slevin and McClelland (1999) also used a single design but in this case they used a single subject quasi-experimental design that resulted in the suggestion that multi-sensory therapy can promote relaxation and may also be useful in the care of people with challenging behaviour.

Interestingly only one paper in this theme sought to highlight the views of an individual with a learning disability. Harker *et al* (2002) explored the subjective experiences of self injurious behaviour of a woman with learning disabilities. It was surprising, given nurses claim to be client centred and holistic that there were not more examples of accounts of individuals who experienced exhibited challenging behaviour themselves. However there were more examples of research that considered the experience of families. Evans *et al* (2001) evaluated the influence of a sibling support group that was set up to help brothers and sisters of children with learning disabilities and challenging behaviour. They were able to demonstrate that, following participation in the structured support group, there was more involvement between siblings and the participants had a greater self esteem and an increased knowledge of learning disability and challenging behaviour. Gates *et al* (1996 and 2001) reported on a comparative study of the effectiveness between gentle teaching, behaviour modification and control interventions. The study involved training parents

in using the different interventions and evaluating the resulting behaviours in their children. Results included the finding that whilst there was no evidence to demonstrate the efficacy of either of the methods of behaviour management there was evidence to suggest that providing training to parents brings about improvements in behaviour of children.

However within the papers that discussed staff attitudes, knowledge and awareness there was a clear finding that all staff, whether qualified or unqualified required regular training and a supportive atmosphere to work with people who challenged services. A study carried out in Scotland for example surveyed health and social care staff in terms of their responses to people with learning disabilities who displayed sexual offending behaviours (McKenzie *et al* 2001). Staff expressed low levels of confidence and only a minority had had specific training in working with people who displayed sexual offending behaviours. There was a big difference in the numbers of health and social care staff who were surveyed (81 social care and 15 nurses) but the researchers were still able to suggest differences including the finding that health staff were more likely to hold negative views towards the person who displayed offending behaviour while social care staff were significantly more likely to hold negative attitudes to the behaviour. The nature of the training offered to staff is also an important factor in the way in which they work with people with challenging behaviour. This was demonstrated by McKenzie *et al* (2003) who examined staff knowledge and practice in relation to the assault cycle that highlights five typical phases of aggressive assault. The research team found that whilst the majority of the staff in the sample had experienced an assault at work, only half had had any staff training on the prevention and management of aggression. Whilst those who had received training were more likely to act in accordance with knowledge of the assault cycle this was not true of all who had been trained. This suggests that there is a need for continual support and training for members of staff involved in working with people with challenging behaviour. This issue was also highlighted by Chung and Corbett (1998) who compared nursing staff who worked in hospital bungalows to those working in the community and suggested that it was not necessarily the issue of challenging behaviour that influenced staff satisfaction but was more likely to be due to management issues.

Two papers in the study explicitly examined the issue of gender and challenging behaviour with Edwards (1999b) asking the question about whose role should physical restraint be? The findings of his study found strong agreement that women have an increased role in physical restraint procedures and that there is reduced dependence upon male staff in such situations. This change is attributed to the provision of better training but the need for further research in this area is highlighted. McKeown *et al* (2003) having researched 38 staff from a variety of professional backgrounds to discern the level of understanding of gender within secure units found that many front line staff were reluctant to highlight gender as an explanation for behaviour. The research team suggested that additional training is needed for staff to be able to link clear research findings regarding the attitudes towards women in secure units and their own practice.

### 6.2.1.5 Methodology

Fifteen papers were assessed as relating primarily to research methodology. Two papers focused on quantitative research the first of which (Gaylor, 2000) explored issues which need to be considered in relation to the inclusion of people with learning disabilities in clinical trials. Gaylor argues that if inclusion criteria are based on IQ scores then this may lead to delays since psychological assessment would be required yet this may be insisted upon by ethics committees and can also lead to the exclusion of a number of people from trials. Issues relating to consent are also explored and it is noted that where both the consent of the individual and the agreement of a caregiver were required then, in some instances the caregiver over rode the individual's wish to participate. Gaylor concludes that the potential advantages of clinical trials should be recognised in relation to people with learning disabilities since those participating may receive additional health monitoring. The development of further clinical trials and the inclusion of quality of life measures to assess the impact of taking medication are recommended.

The other quantitative methodology paper (Gates, 1996) explores issues relating to reliability and validity in the measurement of challenging behaviour. Issues relating to both practice and research are explored and difficulties with the term 'challenging behaviour' are highlighted. It is argued that problems relate to the different methods of assessment used and the reliance upon observers to undertake reliable measurements. It is suggested that both practitioners and researchers should use a battery of types of scales and measurements in order to promote reliability and validity. This is viewed as important both for the purpose of evaluating interventions and for outcome studies.

One paper (Slevin and Sines, 1999) relates generally to the strategies which can be used to promote truthfulness, consistency and transferability in relation to qualitative research. It is argued that rigour in qualitative research can be promoted by using a 'manifold of approaches' and seven techniques are outlined. A further paper (Northway, 2000) explores the need for nurse researchers to adopt a reflexive approach to disability research. Whilst not specific to learning disability it is relevant to nursing research in this field.

Hewitt (1999) explores the use of life story work with people with profound learning disabilities who were in transition from a long stay institution. It is one of the few papers which seeks to explore ways in which people with severe or profound learning disabilities can be involved in research. McNally (2002) provides an account of the methodological issues arising from a pilot survey of self advocacy organisations. Feedback from the pilot study was generally positive and the key issues which emerged related to ethical issues and the process of seeking ethical approval, and the need for documentation to be both accessible and acceptable. In a similar vein Bollard (2003) explores the use of focus groups in a study which sought to examine the experience of people with learning disabilities attending their GP. Bollard also concludes that obtaining consent and the power differentials between researchers and people with learning disabilities are key issues. The use of focus groups is advocated by Bollard but he does recognise that this requires a high level of skill on the part of the researcher and that it may exclude people with limited communication abilities:

the need to develop methods which facilitate the inclusion of this group is therefore noted.

The papers by Hewitt (1999), McNally (2002) and Bollard (2003) may be viewed as seeking to increase the active participation of people with learning disabilities in research. As the initial literature review in this study (Section 2) highlighted the need to seek the views of people with learning disabilities (Gates and Atherton, 2001) has been recognised as has the need to go further than this and to work in collaboration to develop participatory, emancipatory or inclusive research (Ward, 1997; Kiernan, 1997; Chappell, 2000). It is thus positive to note that the biggest group of papers relating to methodology are concerned with this very issue.

One paper (Northway *et al*, 2001) provides an account of how a collaborative approach was achieved at all stages of a project concerning mental health service users. Whilst not focussing on people with a learning disability it is an example of a learning disability nurse transferring their skills in this research approach to work with a different client group. The remaining papers focus on the use of narrative approaches (McClimens, 2002), on the need for learning disability nurses to engage in participatory research (Richardson, 1997), on the process of participatory research (Northway, 1998; McClimens, 1999), on the involvement of people with learning disabilities in the process of data analysis (Richardson, 2002) and on the issue of ending participatory research (Northway, 2000). Taken together these papers provide a range of information for other researchers concerning the processes involved in participatory research. It should be noted, however, that they originate from only 3 researchers and from 2 research centres.

The final paper relating to methodology (Baron *et al*, 1995) is also concerned with collaborative research but, in this instance, it is concerned with the ways in which social scientists can relate to both professionals and patients in the conduct of research. The specific area explored relates to the assessment of quality of care in the context of a study involving community learning disability nurses. An argument is put forward, however, that there is a need for alternative research approaches which would support people with learning disabilities to specify what quality of care means to them.

#### *6.2.1.6 Role of the learning disability nurse*

The role of the learning disability nurse was a strong issue within many of the papers within other themes with nurses exploring nursing practice and the future of a speciality that at times has seemed considerably threatened. However only 10 papers were devoted entirely to the role of the nurse. Most of the research included in this theme is exploratory in nature and considers the views of other professionals, carers and people with learning disabilities. Some claim to reflect a growing confidence in the profession as it consolidates a role in community services. McCray (2003) for example reports that learning disability nurses were feeling particularly positive about their role within multi-disciplinary teams. In a small study involving 10 semi structured interviews McCray found that learning disability nurses felt equipped to meet the challenges posed by a changing health and social care world. Stewart and

Todd (2001) interviewed other professionals about the role of the learning disability nurse and found that they were held in high regard for their breadth of knowledge, qualities and skills.

Other papers reported results that showed mixed perceptions about the role. Narayanasamy *et al* (2002) considered the experiences of learning disability nurses in supporting spiritual needs. They found that sensitivity to religious issues was more apparent than that to spirituality, and that it was the belief system of the nurse that may well influence recognition of the need for spiritual care. Blackmore (2001) in a qualitative study of 8 learning disability nurses recommended an urgent debate into the issue of advocacy as she found that nurses used the term to describe a variety of activities underpinned by opposing ethical principles. Richardson (2000) discovered a mixed perception of nurses among the 6 people with learning disabilities that he worked with as part of a participatory research study. It was encouraging to see that nurses had led support for ordinary living but disturbing to see the continuation of disabling assumptions about people with learning disabilities among nursing staff. Richardson suggests that much of the power within the ordinary housing schemes in which people lived remained with the staff.

There was no consensus about the nature of roles of learning disability nurses. To the contrary Mobbs *et al* (2002) found a wide variation within the practice of community learning disability nurses across England. Many were employed in specialised roles for example challenging behaviour, child health or epilepsy. Despite the differences, many nurses were engaged in health promotion schemes. The latter may reflect the change in the emphasis of the work of community nurses since a study by Parahoo and Barr published in 1996 listed the main perception of learning disability of their roles: health promotion did not feature at all. Their work in profiling nurses working in Northern Ireland found that nurses saw their main roles as, providing support; delivering physical care; behaviour management; and liaison with other services (Parahoo and Barr 1996). Whilst it is difficult to draw firm comparisons from such a small number of studies it may still be worth noting that in a study in 1998 Mansell and Harris found that learning disability nurses were seen to be contributing 5 key roles including health promotion (others being client based interventions; co-ordination and planning of care; training; care management), (Mansell and Harris 1998). Health promotion was a concern of Messant (2003) who reported on a study of two learning disability nursing teams in two London boroughs. Both teams were managed by social services and Messant suggested that there were not enough nurses for the work required and as a result there was no spare capacity to address health facilitation and to develop primary and secondary health care. Messant expressed concern that Social Service managers may not give the required emphasis to the health role of the nurse.

The final paper in this theme considered Quality of Life approaches and suggested that although these have not had a great deal of impact on learning disability nursing to date they could be a basis for collaborative care planning. The authors thus recommended that quality of life be used in nurse education and in the development of research in learning disability nursing (Northway and Jenkins, 2003).

#### *6.2.1.7 Historical research*

Seven papers identified in the review concentrate solely on the history of learning disability nursing or used history as part of a wider argument. There is also a small amount of work by nurses about the history of learning disability generally. The nursing work in the period of this study tends to concentrate on the therapeutic use of personal history and biography and this has been included within the methodology theme. One of the aims of historical work in this field is to provide a history for the purposes of professional socialisation. Gates and Moore (2002) for example seek to offer ‘contemporary nurse practitioners an amazing personal window into the history of learning disability nursing’ by analysing the story of one learning disability nurse who worked in nursing between 1938 and 1981. Mitchell tries to align the history of learning disability within both the wider history of nursing (Mitchell 2000, 2002 and 2003) and also within wider social policy debates (Mitchell 2001). Both Gates and Moore, and Mitchell suggest that the history of people with learning disabilities has been neglected both in terms of their personal biography and also within more general historical discourse. Mitchell (2000) argues that learning disability nursing has been both marginal and problematic within nursing within the past as well as the present. Mitchell (2002) also suggests that historical inquiry provides some answers to questions about the professional location of learning disability nursing in the 21<sup>st</sup> century. Mitchell and Smith (2003) link contemporary work on emotional labour in nursing with the history of learning disability nursing by suggesting that traits of emotional labour were highly valued in the past and can be clearly identified in historical sources.

#### *6.2.1.8 Therapeutic intervention*

As previously noted it was difficult to assign papers to categories since inevitably there was some overlap. For example papers concerning challenging behaviour might well be considered to relate to therapeutic interventions. However, since supporting clients with challenging behaviour is such a large area of work for learning disability nurses it was decided that this should be a separate category. The 6 papers which have been assigned to the therapeutic interventions category therefore have a focus primarily on interpersonal communication.

The first paper (Moulster, 1998) is a qualitative study which sought to explore the opportunities which people with learning disabilities have to access counselling. From qualitative interviews with 9 practitioners who were involved in providing such counselling five main themes emerged – experience, supervision, communication, creative approaches and the value of counselling. It was concluded that creative approaches are currently being used and that communication was not viewed as a barrier. Recommendations are made in relation to the need to develop courses of study for counsellors of people with learning disabilities, the need for a national database of counselling resources, the need for a national register for those involved in providing counselling for people with learning disabilities, further research in relation to the concerns and needs of carers in relation to counselling, and improved awareness amongst people with learning disabilities concerning abuse.

The second study (Read, 2001) is also concerned with counselling but in the specific area of bereavement. Two focus groups were held with bereavement counsellors (n=11) to explore issues relating to their bereavement counselling work. In addition descriptive statistical data concerning use of the bereavement support group for people with learning disabilities over a 12 month period is provided. It is concluded that bereavement counsellors require specific training in relation to the needs of people with learning disabilities and recommendations for the development of specialist services are made.

The next 3 papers all focus on people with profound learning disabilities and/ or additional physical disabilities. Griffiths and Cowman (1999) used non participant observation of 2 clients with profound learning disabilities and semi structured interviews with key workers (n=2) in their pilot study which focused on the interactions of people with profound learning disabilities. They found that people with profound learning disabilities have a strong sensitivity to their environment and that decreasing levels of stimulation correspond to decreasing levels of interaction. They conclude that it is possible for people with profound learning disabilities to learn to interact even when this has not previously been the case and recommend use of King's model of nursing to enhance quality of life for this client group.

Middleton and Hewitt (1999) used a life story approach to construct narratives relating to 6 people with profound learning disabilities (although data from only one client is quoted in the paper). Information was gathered via interviews with key informants and by attendance at staff meetings. The use of life books was found to promote the 'identity' of people with profound learning disabilities and to provide for continuity across changes in place and time.

Gale and Hegarty (2000) aimed to document how nurses and other care staff touch people with learning disabilities in their everyday work and how those people respond to such episodes of touching. Non participant observation was used to observe 9 adults with a learning disability who also had varying degrees of physical impairments. The majority (54.9%) of episodes of touch were functional touch related to physical aspects of care, 26.4% were expressive touch and only 9.8% were therapeutic touch. Qualified nurses accounted for 51.8% of episodes, support workers for 37.8% and non nursing staff for 10.8%. The most frequent response to touch were facial expressions (both positive and negative) including eye contact. It is noted that the findings of this study support other research which suggests that most use of touch is functional touch related to the provision of physical care. Further research in this area focussing on touch as a therapeutic intervention is recommended as is further debate since the use of touch raises ethical issues. This latter point is interesting given that no mention is made in the paper of the ethical issues relating to the research.

The final paper (Bracefield *et al*, 2000) focuses on the views of health and educational professionals concerning the therapeutic use of music. A postal questionnaire achieved a 49% response rate (n=69) and 64% respondents indicated that they had used music to achieve long term improvements for disabled people. Music was most commonly used with children with learning disabilities and children with physical disabilities. This was, however, followed by adults with learning disabilities. 29% of respondents had employed the services of a qualified music therapist. It is concluded that the majority of people with learning disabilities in Northern Ireland do not have

access to professional music therapists and that the shortfall is, in part, being covered by other professionals. The time spent by such professionals in the use of music is viewed as an indication that it is an important part of their role but a lack of formal training in relation to music therapy may mean that music is not being used to best effect. Further research and the involvement of qualified music therapists in the training of other professionals are recommended.

#### 6.2.1.9 International papers

It was not always possible to map the subjects covered in the international papers directly to those used within the review of UK and Irish papers since some other areas of interest emerged whilst others were not apparent. Amongst those subjects evident within the UK / Irish literature but not in the international papers were challenging behaviour, the role of the learning disability nurse, historical aspects of care, therapeutic interventions, and methodology. In part this might be explained by the differing nature of the role of specialist nurses in different health care systems and their non existence within some countries but, since no comparative studies were identified in the current study, further research would be required to clarify this.

One paper was identified which was classified as relating to *educational and professional development* (Walsh *et al*, 2000). This paper surveyed 523 nurses to determine their education and training in relation to working with people with developmental disabilities. The study revealed that whilst many nurses felt that training in this area is important few felt that they had received such specific training. This study may, therefore, be viewed as providing similar findings to studies concerning the educational preparation of health professionals (including nurses) conducted within the UK.

One paper (Heller *et al*, 1998) was classified as relating to *service development and delivery*. This study assessed the impact of moving from nursing homes to community based living over a period of three years. The results showed that those who moved experienced improved health and community functioning as well as greater satisfaction with their lifestyle. Given the move towards hospital closure and the development of community based living in the UK, Ireland and elsewhere this study has international significance. However, most of the literature which is cited is US in origin.

Two papers (Ailey, 2000 and Kozma and Mason, 2003) focus on the experience of health care. Ailey's study is concerned with determining the reliability and validity of the Children's Depression Inventory for use with adolescents with mild learning disabilities. Kozma and Mason reviewed medical records to determine the type and frequency of health needs amongst 55 residents with profound learning disabilities in anticipation of their move to a community setting. Both of these papers can thus be seen as being related to the body of UK and Irish literature which is concerned with the identification and meeting of health needs. However, once again it is interesting to note that whilst Kozma and Mason do make reference to some Australian literature the UK and Irish literature is absent from their review.

Three papers were classified as relating to *nursing care*. Sau-lai Chan and Kwai-sang Yau (2002) were concerned with identifying the nature of interactions between direct care staff and people with learning disabilities living in long stay institutions in Hong Kong. Using a combination of observation and interviews with care staff they found that most staff- resident interactions were concerned with the provision of physical nursing care and that the nature of emotion attached to such interactions was largely neutral. Similar studies have been undertaken elsewhere and there is reference to wider, international, literature. Dijkstra *et al* (1996) is the only paper to be identified from the Netherlands (where there was previously a specialism in learning disability nursing). This paper is concerned with the development of an assessment scale for nursing care dependency which can be used with both people with learning disabilities and those with dementia. Only the first phase of the study (the development of the tool using a Delphi approach) is described in this paper. Koch *et al* (2001) sought to evaluate the provision of a community nursing service by seeking the views of people with learning disabilities (n=3) and their families (n=17). This qualitative study revealed positive feelings concerning the service amongst those who used it. In the literature review included in this paper reference is made to UK studies concerning learning disability nursing.

The final (and largest) group of papers (n=7) to be identified in the international literature relates to *family care*. This category was not included in the review of UK / Irish papers (although some papers did relate with working with families) but is included here since it appeared to be a very dominant theme. This may, perhaps reflect the different roles which nurses play in different health care systems and the fact that responsibility for supporting families of those with learning disabilities may lie with different groups of nurses in different countries. Further research would, however, be needed to examine this tentative hypothesis further.

Two studies (Heaman, 1995 and Browne and Bramston, 1998) were concerned with stress amongst families of those with learning disabilities. Different assessment tools were used but both studies revealed the existence of stressors. In the study undertaken by Heaman the most frequently reported stressor was concern about the child's future whilst Browne and Bramston revealed a number of stressors which they felt were of concern. Recommendations are thus made for the provision of nursing care and support.

Three studies are concerned with the needs of parents. The first (Wong and Wong, 2003) used a focus group approach to determine the needs of families of adults with a severe learning disability resident in a long stay hospital in Hong Kong. The categories to emerge were parenthood, information, parental attitude, coping, family functioning and support. They conclude that the findings have implications for the provision of nursing support for both parents and the residents. Browne and Bramston (1996) investigated quality of life for families of young people with learning disabilities. They found that families of people with learning disabilities had lower overall subjective and objective quality of life scores than did those in the control group but that there was no difference in relation to the 'importance' dimension. They conclude that families of young people with learning disabilities have the same aspirations as other families but that they find it more difficult to satisfy these aspirations. Rodriguez and Jones (1996) used a grounded theory approach to investigate how foster carers of children with learning disabilities adapt in the early

days of placement in their home. They found that parents reported less attention to their own physical needs, a dominance of the parenting role, decreased social interactions and a sense of personal satisfaction. The implications for nursing practice are considered.

Slavik Cowen and Reed (2002) sought to investigate the effects of respite care for children with learning disabilities who came from 'at risk' families. They conclude that public health nurses could enhance their case management strategies by monitoring for care giver burnout as well as ensuring that the child is receiving care which appropriate to their level of need.

The final paper (Bowling and Keltner, 1996) takes a somewhat different perspective on family care since it uses secondary analysis of 62 records from a larger study to determine primary health care usage by 62 2-year old children whose mothers had a learning disability. They conclude that these children did have more frequent referrals for medical and development problems, accidents, and problems with hygiene and discipline than did children of a similar age whose mother did not have learning disabilities. The importance of recognizing the specific needs of such children is thus stressed.

#### 6.2.2 The methodologies and methods used

Overall there were slightly less qualitative studies than there were quantitative (although 25 studies did use a mixed methods approach). Qualitative research is viewed as being an appropriate methodology when the researcher wishes to understand the human experience, uncover social processes, learn cultural patterns or capture unique stories (Liehr and Marcus, 2002). Each of these areas of investigation would appear to be extremely relevant to learning disability nursing research particularly given its' position at the interface between nursing research and wider learning disability research (Figure 1). Indeed some innovative examples of qualitative research were encountered such as the study undertaken by Callan *et al* (1995) which used a grounded theory approach to develop a better understanding of the health needs of one client. It is perhaps, therefore, surprising that qualitative research was not more widely represented in this study.

50 of the papers in this study adopted a quantitative methodology, the majority using a survey approach to collect data. Most of these could best be described as taking a descriptive or exploratory approach which is viewed as suitable where little is known about a phenomenon (LoBiondo-Wood and Haber, 2002). Whilst this might be viewed as appropriate in the context of a developing academic discipline such as learning disability nursing it also lends further strength to the comment above that further qualitative research might also be appropriate.

Surveys enable the researcher to economically gather a large amount of data from a large population but they can also gather superficial information and they demand expertise in relation to issues such as sampling and questionnaire construction (LoBiondo-Wood and Haber, 2002). Many of the papers reviewed for this study used relatively small samples and data collection tools which had not been subjected to testing in terms of reliability and validity. This is in keeping with the concerns

expressed by McConkey (1998) concerning wider learning disability research and limits the extent to which it is possible to generalise. As many authors note in their studies, further research is indicated.

The need for learning disability nursing to provide evidence of effectiveness has been noted (Turnbull, 1997). One way of doing this is to demonstrate cause and effect by means of experimental or quasi-experimental research (Sullivan-Bolyai and Grey, 2002). However, in this review only two papers adopting such an approach were found. Of these one did not randomly assign participants to intervention or control groups and the other took a quasi-experimental approach with the subject acting as their own control. Given the relevance of such research to evidence based practice it would appear that this is research approach where further development may be helpful in learning disability nursing. To achieve this, however, it might be necessary for collaboration between centres to occur since sample size can be crucial and it can be difficult to obtain adequate samples in learning disability research (McConkey, 1998).

### **6.3 The quality of the research**

Some issues pertaining to quality have already been noted in the preceding sections. However, some other areas are also worthy of note.

The majority of papers included in the main part of the study (UK and Ireland) were published in peer reviewed journals many of which are international in status and/ or which have international members of their editorial advisory board. Papers were published in both academic and professional journals the greatest number being in the learning disability specific journals *Journal of Learning Disabilities* and *Learning Disability Practice*. This should mean that there is good access for learning disability nurses and also for others working in the field of learning disabilities (although little is known about their reading habits and further research may be required). However, it may also mean that these are papers which are not readily accessed by nurses working in other fields of nursing despite the fact that they may be involved in supporting people with learning disabilities and that the findings of the research may be relevant to their practice. Further research would, however, be necessary to explore the extent to which nurses from other fields access the learning disability nursing research. It should also be noted that whilst the *Journal of Learning Disabilities* and *Learning Disability Practice* are multi-disciplinary they do have a strong nursing representation both in terms of editorial advisory boards and authors. In contrast only 6 papers were published in the *British Journal of Learning Disabilities*, 1 paper in the *Journal of Intellectual Disability Research* and none in the *Journal of Applied Research in Learning Disabilities*. It is not possible, however, to tell from this review the extent to which this is a result of learning disability nursing authors failing to submit papers to such journals or whether such papers were submitted and rejected.

It is encouraging to note that 11 papers are published in the internationally renowned *Journal of Advanced Nursing*, 6 in the *Journal of Clinical Nursing* and 3 in the *International Journal of Nursing Studies*. Publication in these journals means that nurses working in other fields and also in other countries may easily access the authors' work. This may, however, also mean that such papers are not widely

accessed by other learning disability professionals and academics but once again further research would be needed to explore this possibility.

The use of key words to accompany journal articles which may then be used to assist with indexing such papers with databases can perhaps be viewed more as an indicator of quality in relation to a journal rather than in relation to a particular research study since journal convention will dictate procedure. Nonetheless, some observations are worthy of note here. It has already been indicated in this report that an absence of key words necessitated reliance upon hand searching in some instances. However, the research team also noted that key words seemed, at times, to be used rather arbitrarily and inconsistently. This could lead to difficulties with accessing such papers via computerised databases – what Muir Grey (2001) refers to as the ‘hunting gap’ that arises due to inadequate indexing. Authors and editors may wish to consider this as an important aspect of quality control.

The Centre for Policy in Nursing Research *et al* (2001) noted in their review of nursing research that only 27% of papers studied indicated a funding source for the research reported upon. In this study less than 10% of the studies reviewed indicated a funding source suggesting that learning disability nursing may attract less research funding than other fields of nursing. It might be that other studies simply failed to report this aspect of the research but it could also mean that the majority of published research that took place in learning disability nursing during the period 1995- 2003 was unfunded and this may perhaps account for the presence of so many small-scale studies. Of those studies which did indicate funding the majority gained support from the various national nursing boards. However, there was no evidence of funding being obtained from major charitable bodies or from the Research Councils. The multi-disciplinary nature of learning disability services may mean that in many instances multidisciplinary research (both professional and academic disciplines) may be more appropriate. Nonetheless there is also a need for some discipline specific research within the context of learning disability nursing. In competing for funding, however, there is the danger that learning disability nursing research could be seen as a minority interest in both nursing research and learning disability research. It would thus seem that the issue of funding for learning disability nursing research is one that needs to be addressed as a matter of priority. Further research to identify the actual levels of funding (rather than those reported in the papers) and funding applications submitted but not funded would be helpful. This information could then be used to inform discussion with key funding bodies with a view to expanding the funding available.

The 2001 RAE Nursing and Midwifery Assessment Panel (Unit of Assessment 10, 2001) noted concerns regarding the fragility of some research programmes and the importance of sustainability is similarly noted in the panel criteria and working methods for RAE 2008 (HEFCE *et al*, 2006). It is thus of concern that whilst some of the studies reviewed in this study did demonstrate evidence of sustained lines of inquiry these were confined to a few departments / centres and, in some instances, to single individuals. Given that the current review ends at 2003 it may be that some of the studies reported upon here have subsequently been built upon to form a line of inquiry. Nonetheless it is also important to note that whilst most of the studies reviewed indicated a need for further research this did not always appear to have been forthcoming and, in some instances, similar studies seemed to have been undertaken in isolation of each other. It would thus appear that that issue of sustainability is a

further issue which requires some investigation and attention within the field of learning disability nursing research. The link between this and adequate funding is, however, noted.

Some other issues pertaining to quality were also evident within the studies reviewed. As has already been noted many of the studies were small scale in nature often being confined to one geographical area. In addition some of the studies noted as a limitation the fact that people with severe and profound learning disabilities were not included in the sample. These factors serve to limit the generalisability both to other geographical areas and to the wider client group.

Earlier in this report reference was made to the position in which learning disability nursing research occupies at the interface between nursing research and wider learning disability research (Figure 1). Some clear examples were evident both of the studies reviewed drawing upon both wider nursing research and social science research to inform their development. However, at times, the synthesis between these areas appeared limited and there appeared to be no consensus about key texts or reference to a body of learning disability nursing work within the literature. In reviewing the reference lists of the 14 international studies which were included it was also interesting to note that whilst some did make reference to the UK literature concerning learning disabilities only two papers (Koch *et al*, 2001 and Wong and Wong, 2003) make reference to the UK or Irish learning disability nursing literature. It would thus appear that opportunities for cross fertilisation between countries in relation to this area of work are not being fully utilised.

Gates and Atherton (2001) argue that gathering evidence of effectiveness should include seeking the views of people with learning disabilities. However, whilst some good examples of such an approach were evident in the papers published in this review, and some of the methodological papers focussed upon how such research might be developed, people with learning disabilities were only actively involved in a minority of studies. This would appear to be an area for further development.

In taking such development forward, however, it is important to ensure that ethical principles are upheld. Allen (1997) observed that, in the studies she reviewed, they often failed to provide details as to how consent was obtained. In the papers reviewed for this current study a lack of discussion concerning ethical issues was sometimes evident. This might be due to limitations imposed by publishers and ethical approval could have been obtained but not reported. Nonetheless it would appear to be an area which authors might give greater attention to.

#### **6.4 Trends within the research**

In commenting on trends within the research it must be remembered that only a relatively small (n=142) number of papers were included in the study. Nonetheless, it is possible to determine some trends worthy of note.

First, over the period on which the review focused, there was an increase in the number of papers published per year with a steep rise in the year 1998 and a further gradual rise since then. It is not possible to provide an unequivocal reason as to why

there should have been a rise in 1998 but two possible factors may have contributed. The integration of nurse education into higher education in the mid 1990s meant that increasingly nurse teachers were being required to publish and, given that the last Research Assessment Exercise (RAE) took place in 2001, the years 1998- 2000 were key in terms of publication. In addition, however, it is also interesting to note that 38% of the papers included in this review were published either in the *Journal of Learning Disabilities* (which was launched in 1997) or *Learning Disability Practice* (which was launched in 1998). Whilst it is possible that these papers would have been published in other journals had these two not been launched it is also possible that their publication encouraged learning disability nurses to submit papers for publication. To determine if the overall upward trend in terms of numbers of papers has been maintained after 2003, further research is required.

As with the UK and Irish literature included in this study, the number of international papers published per year seems to have remained constant since 1998 (1-2 per year). However, in contrast the greatest number of international papers published per year was in 1996 when 4 papers were identified.

Although this growth in research must surely be welcomed because it potentially provides an evidence base for practice it is not clear how the research impacts on the practice of nurses themselves. The literature itself does not help directly with this question which although always in the background was not an essential aim of this research. However the literature does help to identify whether research by learning disability nurses is used by other researchers, particularly by other learning disability nurse researchers. In other words is there a developing body of work about learning disability nursing that practitioners can use for their own practice?

In general terms there appears to be a body of work within learning disability nursing but that it does not yet conform to the usual academic practice of building upon itself. Learning disability nursing research tends to take place in isolation from similar nursing work. Put simply, learning disability nurse researchers are less likely to reference other learning disability nurse researchers. Instead they are more likely to draw on the work of other disciplines such as psychology, education and other branches of nursing. It is certainly important to use such wide sources of research but this could be done alongside building existing learning disability nursing knowledge.

This may well be reflective of the outlets for publication. The research found that although a large number of research papers by learning disability nurses were published in international nursing journals, few were published in international learning disability journals. This begs the question of who researchers are writing for? If researchers are writing to influence practice then it may be expected that they would write for journals that are widely read by practitioners. Unfortunately there is currently little evidence about the reading habits of learning disability nurses in practice although it is probably safe to assume that many more read *Learning Disability Practice* or the *Nursing Times* or *Nursing Standard* than the *Journal of Advanced Nursing*. However practice can be influenced by education, and a culture of research that starts with published sources can seep through to the oral tradition of nursing. Whatever the position of such research usage, this study has shown that there is no single body of work that is being used by researchers. Instead of this they are

tending to rely on a range of literature from different disciplines to develop and reflect upon.

In relation to the themes which form the focus of the studies reviewed it is difficult to determine trends due to the small numbers in some categories and the fact that many of the themes reflect the overall trend towards more papers being published post 1998. Nonetheless it is interesting to note that, in relation to health care experiences, 25 of the 28 papers were published after 1998. This may perhaps be seen to reflect both growing concern in relation to the health needs of people with learning disabilities and the fact that the role of the learning disability nurse has, in many areas, become more focused on health promotion in recent years. In relation to therapeutic interventions, however, it is perhaps of concern that only a small number of papers fell into this theme and that none were published over the final two years of the study.

The *Journal of Learning Disabilities* published the greatest number of papers included in this review and each of the themes was evident in these papers. However, both *Learning Disability Practice* and the *British Journal of Nursing* covered 6 of the 8 themes and the *Journal of Advanced Nursing* 5. This suggests that these 4 journals provide the best coverage of topics but it must be remembered that they only account for just over half (54%) of the papers included. There would thus appear to be a need for learning disability nurses to consult a wide range of journals to view papers which are relevant to their practice.

When the methodologies used in studies are considered alongside the years of publication it can be seen that, in general, the overall trend corresponds to the rise in numbers of papers published post 1998. Qualitative studies peaked in 1998 with ten papers being published and whilst there was a dip the following year the numbers again began to rise in 2002-2003. The peak in relation to quantitative studies was in 2001 with 11 papers being published in that year. The numbers of mixed methods studies remained relatively stable over the entire study period although the greatest number (n=5) were published in 2001 and 2002. The majority of papers in the 'other' category were published post 2000.

## **6.5 Gaps in the research**

Some key gaps the research were evident from the review undertaken in this study. First, as has already been noted, there appears to be a gap in relation to the need for research as identified in one study being translated into further research and subsequent publications. Second there appears to be a gap in relation to methodology and methods. Allen (1997) noted duplication within learning disability research rather than replication. This was certainly true in the studies reviewed here. For example whilst a number of studies focused on health assessment, differing tools were used. A similar situation was evident in those studies which focused on the role of the learning disability nurse. This means that it is sometimes difficult to make comparisons between studies undertaken in differing areas or at different points in time. McConkey (1998) suggested that few longitudinal studies are evident in learning disability research and this was again true in this review, the study by Martin (2003) being an exception. Limited use of experimental and quasi-experimental research designs was

also evident although such approaches are important in examining effectiveness of interventions.

A third key gap in the research is that which exists due to the absence of UK and Ireland wide studies. This is particularly pertinent since devolution of political decision making has led to differing policies for services for people with learning disabilities and also for nursing within the different countries. There would thus appear to be a good case for the development of larger studies which would enable the impact of differing policy contexts on the role of the learning disability nurse to be examined.

A fourth key gap is the absence of any international studies undertaken by nurses specialising in the care of people with learning disabilities or concerning such nursing practice. Given that there are international concerns about the health disparities experienced by people with learning disabilities, and given that nurses would appear to have a key role to play in addressing such disparities, this would appear to be a gap which, along with the others identified here, should be addressed.

## **7. Conclusion and Recommendations**

### **7.1 Limitations**

Before drawing conclusions it is important to note the limitations to this study. Whilst every effort has been made to identify all of the research papers published by, or concerning, learning disability nursing during the period 1995- 2003 it is possible that some papers may not have been identified. There are a number of reasons for this many of which have already been discussed in this report and which relate to the difficulties encountered in searching and in identifying those authors who are learning disability nurses.

This was particularly true in relation to those studies that originated from outside of the UK or Ireland where it must be noted that only papers published in the English language were included. Thus there are likely to be further papers written by nurses which focus on people with learning disabilities and/ or their families which it has not been possible access. In addition only 14 papers such papers were identified which makes it difficult to draw definitive conclusions.

In focussing on only the published research in this field it should also be noted that this review does not present a picture of all of the research which was undertaken by learning disability nurses during this period. It was not possible, in the context of this study, to access and review the 'grey literature' of unpublished research reports, undergraduate and post-graduate dissertations. This is, however, an area worthy of further investigation and could usefully form the basis of a subsequent research study.

A final, but inevitable, limitation of a study of this type lies in the fact that it provides only a snapshot in time and ends at the year 2003. Whilst it does, therefore, provide a baseline (given that no similar studies had been undertaken) the need for a longitudinal approach and further research is noted.

### **6.2 Conclusions**

Despite the limitations noted above it is possible to draw some conclusions from this review.

The starting point for this study was the suggestion that research in the field of learning disability nursing was limited. From undertaking the review it can be concluded that whilst this may be the case, it is an area which appears to be expanding. Some positive signs are evident such as the number of papers where a learning disability nurse was an author, the growing number of published papers, the range of journals in which the papers are published, and the emergence of some discernable lines of inquiry.

As a young academic discipline, however, there are also some key areas that need to be addressed if such development is to be translated into sustainable programmes of research in this field. These areas operate at a variety of different levels starting with the ability of students, qualified practitioners and academics to search and synthesise the existing literature so that subsequent studies can build in a coordinated way on the research that already exists. The research team found the task of accessing learning

disability nursing research through the standard electronic databases to be much more difficult than expected. The report has highlighted the problematic usage of key words and also the absence of a single database that indexes all of the journals in which learning disability nurses write. This must cause particularly difficulties for students of learning disability nursing who are learning the skills of research usage. It is also likely to be one of the reasons that learning disability nurses find it difficult to access research. It may also be a contributory factor to the finding that there is a lack of synthesis between areas of research that are relevant to learning disability and the failure, at times, to access the learning disability nursing research.

From the papers excluded from the study it can also be concluded that learning disability nurses are publishing a large amount of papers which can best be described as literature reviews. However, the absence of a clear search strategy within such papers means that it is difficult to see how the information discussed builds upon and extends existing knowledge. Attention in this area would assist in building the theory base for learning disability nursing and also in identifying the need for subsequent research. Nonetheless it is also important to note the conclusion that where recommendations for further research are made in published studies, action in relation to such recommendations was not always evident within the papers reviewed for this study.

Within this report a number of areas for further research have been identified and thus it can be concluded that there is a considerable research agenda which needs to be addressed within the field of learning disability nursing. However, attention is also needed to the development of methodologies and methods that allow both for a full range of research questions to be addressed and, where possible, for the active involvement of people with learning disabilities. It is also important that research undertaken is disseminated and whilst this review has identified a growth in papers in 1998 further growth since that point has been very limited. In addition despite the wide range of outlets for publication it was notable that few were published in international learning disability journals, preference in relation to international journals being given to nursing journals.

To support further developments collaboration between groups of researchers within the UK and Ireland as well as with those working in this area in other countries would appear to be necessary. This would facilitate greater coordination of research and also the development of larger scale studies around areas of mutual concern. To make this a reality, however, funding would be required, and from this study it can be concluded that much of the research currently undertaken is not funded.

### **7.3 Recommendations**

On the basis of this study the following recommendations are made:

- That learning disability nursing lecturers support students on both pre-registration and post registration courses to develop their skills in accessing research relevant to their practice via the use of electronic databases. This should include guidance regarding the use of multiple databases, multiple terms, and the need to search a range of journals as well as the need to draw

upon nursing research, learning disability research and learning disability nursing research.

- That authors and editors pay careful attention to the use of key words which accompany papers and which assist in indexing the papers with the various databases.
- That peer reviewers and editors scrutinise papers submitted for publication carefully to determine the extent to which they locate the research in the context of existing knowledge and build upon existing research.
- That authors writing scholarly reviews of the literature consider including the search strategy used in the papers they write for publication in order to contribute in a more systematic way to the development of the theory base for learning disability nursing and to identify further research questions.
- That researchers seek to extend the range of research designs used to include the use of longitudinal, experimental and quasi-experimental approaches where appropriate. In addition consideration should be given to the wider use of replication studies particularly where valid and reliable data collection tools have been developed.
- That the recommendations for further research highlighted in the studies reviewed (Section 6.2.1) are acted upon.
- That researchers continue to develop ways by which the views of people with learning disabilities can more directly inform learning disability nursing research.
- That the issue of funding for learning disability nursing research be explored as a matter of priority. This should include research to determine the actual levels of funding for learning disability nursing research and to determine the number of successful funding bids as a percentage of the total number of bids submitted.
- That researchers seek to develop collaborations which will enable larger scale studies to be undertaken over a wider geographical area. Specifically some UK and Ireland wide studies should be developed as should some international studies which allow for comparisons to be made.
- That further research is undertaken to identify the 'grey literature' written by, or concerning learning disability nursing.
- That further research is undertaken to determine the extent to which learning disability nurses access and utilise research evidence.
- That further research is undertaken to determine the extent to which learning disability nursing research is taken up by nurses working in other fields of nursing and by practitioners and academics from other disciplines working in learning disabilities.
- That this study is repeated in order that developments in research in the field post 2003 can be identified.

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## **Appendix 1**

### **The Proforma Used to Document Analysis of Papers**

<b>Title of paper:</b>
<b>Author(s):</b>
<b>Professional background of author(s) if stated:</b>
<b>Institutional affiliation of author(s):</b>
<b>Year of publication:</b>
<b>Name of journal:</b>
<b>Volume / Part/ Page numbers:</b>
<b>Research study?</b>
<b>Methodology paper?</b>
<b>Focus of the study/ paper:</b>
<b>Stated methodology / methods used:</b>
<b>Country in which study undertaken:</b>
<b>Sample size and characteristics (where relevant):</b>

**Key results / findings:**

**Recommendations / conclusions of the study:**

**Assessed strengths/ weaknesses of the study:**

**Source of funding (if stated):**

**Any other comments:**

**Reviewed by:**

## **Appendix 2**

### **Results of the Searches of Databases Using Key Words**

## CINAHL

A search of CINAHL produced 134 papers after duplicates had been eliminated. When titles/ abstracts were reviewed 21 were screened out since they were either not specific to learning disabilities or they were abstracts of PhD theses and hence not published research.

Search term 1	Search term 2	Limits applied?			Number of papers identified
		1995-2003	Research	English Language	
Learning disability	Nursing	Y	Y	Y	36
	Nurses	Y	Y	Y	32
Learning disabilities	Nursing	Y	Y	Y	37
	Nurses	Y	Y	Y	32
Learning difficulties	Nursing	Y	Y	Y	4
	Nurses	Y	Y	Y	4
Mental retardation	Nursing	Y	Y	Y	47
	Nurses	Y	Y	Y	45
Developmental disabilities	Nursing	Y	Y	Y	12
	Nurses	Y	Y	Y	10
Intellectual disabilities	Nursing	Y	Y	Y	1
	Nurses	Y	Y	Y	1
Mental handicap	Nursing	Y	Y	Y	5
	Nurses	Y	Y	Y	6

## BNI

A search of the British Nursing Index produced 134 papers warranting further investigation after duplicates have been eliminated.

Search term 1	Search term 2	Limits applied?			Number of papers identified
		1995-2003	Research	English Language	
Learning disability	Nursing	Y	N	N	206
Learning disability	Nurses	Y	N	N	57
Learning disabilities	Nursing	Y	N	N	443
	Nurses	Y	N	N	118
Learning difficulties	Nursing	Y	N	N	7
	Nurses	Y	N	N	7
Mental retardation	Nursing	Y	N	N	44
	Nurses	Y	N	N	19
Developmental disabilities	Nursing	Y	N	N	5
	Nurses	Y	N	N	3
Intellectual disabilities	Nursing	Y	N	N	3
	Nurses	Y	N	N	0
Mental handicap	Nursing	Y	N	N	6
	Nurses	Y	N	N	0

## Medline

A search of Medline produced 347 papers warranting further investigation after duplicates have been eliminated. A number of papers (71) screened out which were not learning disability specific or which were not English language leaving a total of 270.

Search term 1	Search term 2	Limits applied?			Number of papers identified
		1995-2003	Research	English Language	
Learning disability	Nursing	Y	N	N	63
	Nurses	Y	N	N	70
Learning disabilities	Nursing	Y	N	N	61
	Nurses	Y	N	N	73
Learning difficulties	Nursing	Y	N	N	9
	Nurses	Y	N	N	8
Mental retardation	Nursing	Y	N	N	132
	Nurses	Y	N	N	100
Developmental disabilities	Nursing	Y	N	N	51
	Nurses	Y	N	N	43
Intellectual disabilities	Nursing	Y	N	N	4
	Nurses	Y	N	N	4
Mental handicap	Nursing	Y	N	N	12
	Nurses	Y	N	N	8

## ASSIA

The search of ASSIA produced 171 papers after duplicates have been eliminated. This database produced a lot of papers published in the Nursing Times which were not identified elsewhere. However, these were not research papers.

Search term 1	Search term 2	Limits applied?			Number of papers identified
		1995-2003	Research	English Language	
Learning disability	Nursing	Y	N	Y	58
	Nurses	Y	N	Y	75
Learning disabilities	Nursing	Y	N	Y	52
	Nurses	Y	N	Y	79
Learning difficulties	Nursing	Y	N	Y	5
	Nurses	Y	N	Y	4
Mental retardation	Nursing	Y	N	Y	2
	Nurses	Y	N	Y	1
Developmental disabilities	Nursing	Y	N	Y	3
	Nurses	Y	N	Y	2
Intellectual disabilities	Nursing	Y	N	Y	0
	Nurses	Y	N	Y	0
Mental handicap	Nursing	Y	N	Y	7
	Nurses	Y	N	Y	8

## Embase

The Embase search produced 105 papers after duplicates had been eliminated. Among these were a large amount of papers which were not learning disability specific – relating to children with complex health problems, people with mental health problems and older people. Identified a lot of non nursing papers despite the inclusion of nurses or nursing in the search terms

Search term 1	Search term 2	Limits applied?			Number of papers identified
		1995-2003	Research	English Language	
Learning disability	Nursing	Y	N	Y	6
	Nurses	Y	N	Y	13
Learning disabilities	Nursing	Y	N	Y	12
	Nurses	Y	N	Y	15
Learning difficulties	Nursing	Y	N	Y	3
	Nurses	Y	N	Y	2
Mental retardation	Nursing	Y	N	Y	42
	Nurses	Y	N	Y	22
Developmental disabilities	Nursing	Y	N	Y	19
	Nurses	Y	N	Y	7
Intellectual disabilities	Nursing	Y	N	Y	1
	Nurses	Y	N	Y	2
Mental handicap	Nursing	Y	N	Y	4
	Nurses	Y	N	Y	1

## PsychInfo

The PsychInfo search identified 230 papers after duplicates have been eliminated. A number were eliminated because they were books or PhD abstracts.

Search term 1	Search term 2	Limits applied?			Number of papers identified
		1995-2003	Research	English Language	
Learning disability	Nursing	Y	N	Y	47
	Nurses	Y	N	Y	40
Learning disabilities	Nursing	Y	N	Y	30
	Nurses	Y	N	Y	26
Learning difficulties	Nursing	Y	N	Y	20
	Nurses	Y	N	Y	12
Mental retardation	Nursing	Y	N	Y	59
	Nurses	Y	N	Y	32
Developmental disabilities	Nursing	Y	N	Y	47
	Nurses	Y	N	Y	17
Intellectual disabilities	Nursing	Y	N	Y	11
	Nurses	Y	N	Y	7
Mental handicap	Nursing	Y	N	Y	7
	Nurses	Y	N	Y	4

Total number of papers identified from stage 2 after duplicates and papers clearly not meeting the inclusion criteria have been eliminated: 404

## **Appendix 3**

### **Papers Included in the Study from the UK and Ireland**

Alaszewski,A. Manthorpe, J. Ayer, S.(1998) *Assessing and managing risk in nursing education and practice: supporting vulnerable people in the community*, English National Board for Nursing, Midwifery and Health Visiting

Alaszewski,A. Gates, B. Ayer,S. Manthorpe,J. (2001) *Diversity and Change: the Changing Roles and Education of Learning Disability Nurses*, English National Board for Nursing, Midwifery and Health Visiting

Alderwick, A. Rouff,C. Sandford,E. (1998) Cinderella is coming home. *Learning Disability Practice*, 1,2,21-23

Aylott, J.T. (1996) Community learning Disability Teams. *Community Nurse Specialist*, 5,8,488-492

Bailey, A.B. (2000) Police policies on the investigation of sexual crimes committed against adults who have a learning disability: a preliminary study. *Journal of Learning Disabilities*, 4,2,129-139

Bailey, A. Barr, O. Bunting, B. (2001) Police attitudes toward people with intellectual disability: An evaluation of awareness training *Journal of Intellectual Disability Research*, 45, 4, 344-350

Baron, S. Gilloran, A. Schad, D. (1995) Researching with nurses and patients: from subjects to collaborators *Social Sciences in Health*, 1, 3, 175 - 188

Barr, O.Gilgunn,J., Kane, T. (1999) Health screening for people with learning disabilities by a community learning disability nursing service in Northern Ireland *Journal of Advanced Nursing*, 29, 6, 1482-91

Blackmore, R. (2001) Advocacy in nursing. Perceptions of learning disability nurses *Journal of Learning Disabilities*,5, 3, 221 - 234

Boarder, J. H. (2002) The perceptions of experienced community learning disability nurses of their roles and ways of working: An exploratory study *Journal of Learning Disabilities*, 6, 3, 281-296

Bollard, M. (1997) Promoting the health care needs of people with learning disabilities *British Journal of Community Health Nursing*, 2,1, 46-51

Bollard, M. (1998) Training need in primary care *Learning Disability Practice*,1,1, 16 - 20

Bollard, M. (1999) Improving primary health care for people with learning disabilities *British Journal of Nursing*, 8,18, 1216-21

Bollard, M. (2003) Going to the doctors: the findings from a focus group with people with learning disabilities *Journal of Learning Disabilities*, 7, 2,156 – 165

- Bracefield, H. Kirk-Smith, M. Slevin, E. (2000) Music therapy in Northern Ireland: the provision for people with learning disabilities *Journal of Learning Disabilities*, 4,1, 63-76
- Bradley, P. (1998) Perceptions of health and social care need - an exploratory study *Learning Disability Practice*,1, 4, 10 – 14
- Broughton, S. (2002) A review of the literature: interventions to maximise capacity to consent and reduce anxiety of women with learning disabilities preparing for a cervical smear test *Health Services Management Research*,15, 3, 173 - 85
- Broughton, S. Thomson, K. (2000) Women with learning disabilities: risk behaviours and experiences of the cervical smear test, 32, 4, 905 – 912
- Burns, M. Bird, D. Leach, C. Higgins, K. (2003) Anger management training: the effects of a structured programme on the self reported anger experience of forensic inpatients with learning disability, *Journal of Psychiatric and Mental Health Nursing*, 10, 5, 569 – 577
- Callan, L. Gilbert,T. Golding,K. (1995) Assessing health needs in people with severe learning disabilities: a qualitative approach *Journal of Clinical Nursing*, 4,5, 295-302
- Carlson, T. Hames, A. Wilson, M. (2003) What is the community team learning disability? *Primary Health Care*, 13,5, 37-41
- Carlson, T. Hyde, S. Homes,A. (2003) Lifespan or separate: which service is best? *Learning Disability Practice*, 6,10, 16 - 21
- Casey,P. Barr, O. (1995) Factors and circumstances perceived as contributing to mental health problems in people with learning disabilities *Journal of Psychiatric & Mental Health Nursing*, 2, 4, 247-8
- Cash, J. Turner,S. Raha, J. (2000) The personal touch *Learning Disability Practice*, 3, 2, 19 - 22
- Chung, M. Corbett, J. (1998) The burnout of nursing staff working with challenging behaviour clients in hospital-based bungalows and a community unit *International Journal of Nursing Studies*, 35,1,2, 56-64
- Codling, M. (2001) Compelling Evidence *Learning Disability Practice*,4, 4,22 - 25
- Courell, D. (1997) The hospitalisation of people with severe learning difficulties...the experience of carers and nursing staff *Nursing Review (Ireland)*, 16,1, 21 - 3
- Culley, L. Genders, N(1999) Parenting by people with learning disabilities: the educational needs of the community nurse *Nurse Education Today*, 19, 6, 502-8
- Davies, P. Lado, A. Northway, R. Bennett, G. Williams, R. Moseley, L. Mead, D. (2002) An evaluation of student nurses experiences of being a researcher in a mental health research project *Nurse Education Today*, 22, 7, 518-26

- Dickson, K. Paxton, D. McKenzie, K. (2002) Moving on *Learning Disability Practice*, 5, 2, 11 - 13
- Dobson, S. Dodsworth, S. Miller, M. (1998) Evaluation of an approach for adults with profound learning disabilities *International Journal of Language & Communication Disorders*, 33, 392 – 396
- Dobson, S. Dodsworth, S. Miller, M. (2000) Problem-solving in small disciplinary teams: A means of improving the quality of the communication environment for people with profound learning disability *British Journal of Learning Disabilities*, 28, 1, 25-30
- Donovan, J. (2002) Learning disability nurses' experiences of being with clients who may be in pain *Journal of Advanced Nursing*, 38, 5, 458-66
- Doyle, C. Mitchell, D. (2003) Post-traumatic stress disorder and people with learning disabilities. A literature based discussion *Journal of Learning Disabilities*, 7, 1, 23 – 33
- Dunniece, U. Slevin, E. (2000) Nurses' experiences of being present with a patient receiving a diagnosis of cancer *Journal of Advanced Nursing*, 32, 3, 611 - 18
- Dunniece, U. Slevin, E. (2002) Giving voice to the less articulated knowledge of palliative nursing: an interpretative study *International Journal of Palliative Nursing*, 8, 1, 13 – 20
- Edwards, R. (1999) The laying on of hands: nursing staff talk about physical restraint *Journal of Learning Disabilities for Nursing, Health and Social Care*, 3, 3, 136 – 146
- Edwards, R. (1999) Physical restraint and gender: whose role is it anyway? *Learning Disability Practice*, 2 ,3, 12 – 15
- Etchells, J. Kniveton, K. Longshaw, K. Mitchell, D. (1999) Dual qualification education and training: the learning disability experience *Mental Health Care*, 2, 12, 412 – 5
- Evans, J. Jones, J. Mansell, I. (2001) Supporting siblings: evaluation of support groups for brothers and sisters of children with learning disabilities and challenging behaviour *Journal of Learning Disabilities*, 5, 1, 69-78
- Fisher, M. Coyle, D. (1999) Involving service users in professional nurse education in Wales *Journal of Learning Disabilities*, 3, 4, 209-13
- Gale, E. Hegarty, J. (2000) The use of touch in caring for people with learning disability *British Journal of Developmental Disabilities* 46 (2) 97 – 108
- Gates, B. (1996) Issues of reliability and validity in the measurement of challenging behaviour (behavioural difficulties) in learning disability: a discussion of implications for nursing research and practice *Journal of Clinical Nursing*, 5, 1, 7-12

Gates, B. Moore, D. (2002) Annie's story: the use of oral history to explore the lived experience of a learning disability nurse in the 20th century *International History of Nursing Journal*, 7, 2, 50-59

Gates, B. Newell, R. Wray, J. (2001) Behaviour modification and gentle teaching workshops: management of children with learning disabilities exhibiting challenging behaviour and implications for learning disability nursing *Journal of Advanced Nursing*, 34, 1, 86-95

Gates, B. Wray, J. Newell, R. (1996) Challenging behaviour in children with learning disabilities *British Journal of Nursing*, 5, 19, 1189 - 94

Gaylor, M. (2000) Trials and Tribulations *Learning Disability Practice*, 2, 4, 12 – 15

Gilbert, T. (2003) Exploring the dynamics of power: a Foucauldian analysis of care planning in learning disabilities services *Nursing Inquiry*, 10, 1, 37 – 46

Gilbert, T. Cochrane, A. Greenwell, S. (2003) Professional discourse and service cultures: an organisational typology developed from health and welfare services for people with learning disabilities *International Journal of Nursing Studies*, 40, 781 – 793

Griffiths, C. Cowman, S. (1999) Towards understanding the interactions of people with a profound learning disability: a pilot study *Nursing Review (Ireland)*, 17, 1/2, 35 – 39

Harker Longton, W. Fish, R. (2002) Cutting doesn't make you die' One woman's views on the treatment of her self injurious behaviour *Journal of Learning Disabilities*, 6, 2, 137 – 151

Hart, S. (1998) Learning disabled people's experiences of general hospitals *British Journal of Nursing*, 7, 8, 470 – 7

Hart, S. (1999) Meaningful choices: consent to treatment in general health care settings for people with learning disabilities *Journal of Learning Disabilities for Nursing, Health and Social Care*, 20 – 26

Haut, F. Hull, A. Irons, A. (2000) Learning disability staff: a response to psychiatric teaching *British Journal of Developmental Disabilities*, 28, 4, 154 – 6

Hebron, C. (1999) A Record of partnership *Learning Disability Practice*, 2, 1, 12-16

Hewitt, H. (2000) Learning disability nursing. A life story approach for people with profound learning disabilities *British Journal of Nursing* 9, 2, 90- 5

Hickson, K. Poole, H. (1998) Respite care: in the spotlight *Learning Disability Practice* 1, 3, 6-9

- Jenkins, R. Harris, P. (1999) Perceptions of registered nurses on the use of psychotropic medication for people with learning disabilities *Journal of Learning Disabilities for Nursing, Health and Social Care* 3, 4, 204 – 08
- Kaye, N. Allen, D. (2002) Over the top? Reducing staff training in physical interventions *British Journal of Learning Disabilities*, 30, 3, 129-132
- Kwiatk, E. McKenzie, K. (2002) Twice the professional? *Learning Disability Practice*, 5, 10, 8 – 11
- Lindop, E. Read, S. (2000) Palliative care needs for people who have a learning disability: exploring the needs of qualified district nurses *European Journal of Oncology Nursing*, 4, 1, 59 – 61
- Lindop, E. Read, S. (2000) District nurses needs: palliative care for people with learning disabilities *International Journal of Palliative Nursing* 6, 3, 117 – 122
- Maggennis, C. Slevin, E. Cunningham, J. (1999) Nurses' attitudes to the extension and expansion of their clinical roles *Nursing Standard* 13, 51, 32 – 36
- Malin, N. (2000) Evaluating clinical supervision in community homes and teams serving adults with learning disabilities *Journal of Advanced Nursing* 31, 3, 548-57
- Mansell, I. Harris, P. (1998) Role of the Registered Nurse Learning Disability within community support teams for people with learning disabilities *Journal of Learning Disabilities*, 2, 4, 190-4
- Mansell, I. Bennett, G. Torrance, C. Fairbairn, G. (2002) The role of the nurse lecturer in the supervision of students' essays, projects and assignments: results of an all Wales questionnaire survey *Nurse Education Today*, 22, 7, 511- 7
- Manthorpe, J. Alaszkeski, A. Gates, B. Ayer, S. Motherby, E. (2003) Learning disability nursing: user and carer perceptions *Journal of Learning Disabilities* 7, 2, 119 – 35
- Marshall, D. Foster, I. (2002) Learning disability nursing. Providing a healthcare input to children in special schools *British Journal of Nursing*, 11, 1, 28-30, 32-5
- Marshall, D. McConkey, R. Moore, G. (2003) Obesity in people with intellectual disabilities: the impact of nurse led health screening and health promotion activities *Journal of Advanced Nursing*, 41, 2, 147 – 153
- Marsland, L. (2001) Looking to the future: career guidance received by students qualifying as learning disability nurses *Journal of Learning Disabilities* 5 (4) 353 – 67
- Martin, G. (2003) Annual health reviews for patients with severe learning disabilities: five years of a combined GP/CLDN clinic *Journal of Learning Disabilities*, 7, 1, 9-21
- Matthews, D. Hegarty, J. (1997) The OK Health Check assessment checklist for people with learning disabilities *British Journal of Learning Disabilities*, 25, 4, 138-143

- McAllister, A. Bailey, A. Barr, O. (2002) Training in joint investigation of alleged crimes against people with learning disabilities in Northern Ireland *Journal of Adult Protection*, 4, 2, 21-7
- McClimens, A.(1999) Participatory research with people who have a learning difficulty: journeys without a map *Journal of Learning Disabilities*, 3, 4, 219-28
- McClimens, A.(2002) All I can remember were tablets":Pat's story. *Journal of Learning Disabilities*,6, 1, 73-88
- McConkey, R. Moore,G. Marshall,D. (2002) Changes in the attitudes of GPs to the health screening of patients with learning disabilities *Journal of Learning Disabilities*, 6, 4, 373 – 384
- McCray, J. (2003) Interprofessional practice and learning disability nursing *British Journal of Nursing*, 12, 22, 1335 – 44
- McCray, J. Carter, S. (2002) A study to determine the qualities of a learning disability practitioner *British Journal of Nursing*, 11, 21, 1380-8
- McIntosh, P. (1998) How nurses cope with ongoing grief in client work: an exploratory study *Journal of Learning Disabilities for Nursing, Health and Social Care*, 2, 3, 124 – 30
- McKenzie, K. Baxter,S. Paxton,D. Murray, G. (2002) Picking up the signs *Learning Disability Practice*, 5, 3, 16 – 19
- McKenzie, K. Chalmers,E. Paxton,D. (2003) Hitting the spot *Learning Disability Practice*, 6, 3, 15-19
- McKenzie, K. Matheson,E. McKaskie,K. Paxton, D. Michie, A. Murray, G (2001) Health and social care staff responses to working with people with a learning disability who display sexual offending type behaviours *The Journal of Sexual Aggression*, 7, 1, 56-66
- McKenzie, K. Matheson, E. Paxton, D. (1999) An examination of the pattern of challenging behaviour referrals to a community learning disability nursing service *Health Bulletin*57 (4) 262 – 6
- McKenzie, K.. Paxton,D. Matheson,E. (2000) Professional composition of community learning disability teams in Scotland: implications for service provision *Health Bulletin*, 58, 3, 192 – 7
- McKeown, M. Anderson,J. Bennett,A. (2003) Gender politics and secure services for women: reflections on a study of staff understandings of challenging behaviour *Journal of Psychiatric & Mental Health Nursing*, 10, 5, 585-591

- McNally, S. (2003) A survey of self-advocacy groups for people with learning disabilities in an English region: Part 2 *Journal of Learning Disabilities*, 7, 3, 231-250
- McNally, S. (2002) A survey of self-advocacy groups for people with learning disabilities in an English region. Part 1 *Journal of Learning Disabilities*, 6, 2 185-199
- Messent, P. (2003) An evaluation of community learning disability nurse teams in two London boroughs *British Journal of Community Nursing*, 8, 9, 411-20
- Middleton, D. Hewitt, H.L. (1999) Remembering as social history: identity and life history in transitions of care for people with profound learning disabilities *Narrative Inquiry*, 9,1, 97 – 121
- Mitchell, D.(1996) Learning disability nursing in the post war period *International History of Nursing Journal*, 1, 4, 20-33
- Mitchell, D. (2000) The origins of learning disability nursing *International History of Nursing Journal*, 4, 1, 10-6
- Mitchell, D. (2001) Nursing and social policy in the 1930's: a discussion of mental deficiency nursing *International History of Nursing Journal*, 6,1, 56-61
- Mitchell, D. (2003) A chapter in the history of nurse education: learning disability nursing and the Jay Report *Nurse Education Today*, 23, 5, 350-361
- Mitchell, D. (2002) A contribution to the history of learning disability nursing *NT Research*, 7, 3, 201 – 211
- Mitchell, D. Smith, P. (2003) Learning from the past. Emotional labour and learning disability nursing *Journal of Learning Disabilities*,7, 2, 109-117
- Mobbs, C. Hadley,S. Wittering,R. (2001) An exploration of the role of the community nurse, learning disability, in England *British Journal of Learning Disabilities*, 30, 1, 13 - 8
- Moore,G. McConkey,R. Duffy, M. (2003) The role of the school nurse in special schools for pupils with severe learning difficulties *International Journal of Nursing Studies*, 40, 7, 771-9
- Moulster, G (1998) Improving Access to Counselling for People with Learning Disabilities *Learning Disability Practice* 1 (2) 14 – 17
- Murray, G. Powell, H. Sinclair, B. Simpson, N. McKenzie,K. (2001) A change for the better *Learning Disability Practice*, 3, 5, 12 – 15
- Narayanasamy, A. Gates,B. Swinton,J. (2002) Learning disability nursing. Spirituality and learning disabilities: a qualitative study *British Journal of Nursing*, 11, 14, 948 – 57

- Ng, J Li,S. (2003) A survey exploring the educational needs of care practitioners in learning disability settings in relation to death, dying and people with learning disabilities *European Journal of Cancer Care*, 12, 1, 12 – 9
- Norman, I. (1998) Priorities for mental health and learning disability nurse education in the UK: a case study *Journal of Clinical Nursing* 7, 433-441
- Norman, I. (1998) The changing emphasis of mental health and learning disability in the UK and ideal models of its future development *Journal of Psychiatric & Mental Health Nursing* 5, 41-51
- Northway, R. (1998) Engaging in participatory research: some personal reflections (In the field of learning disabilities) *Journal of Learning Disabilities for Nursing, Health and Social Care*, 2, 3, 144-9
- Northway, R. (2000) Disability, nursing research and the importance of reflexivity *Journal of Advanced Nursing*, 32, 2, 391-7
- Northway, R.(2000) Ending participatory research? *Journal of Learning Disabilities*, 2, 3, 144-9
- Northway, R. (2003) Participative research. In Jukes, M., Bollard, M. (eds) *Contemporary Learning Disability Practice*, Salisbury: Quay Books. 3 - 19
- Northway, R. Jenkins, R (2003) Quality of life as a concept for developing learning disability nursing practice? *Journal of Clinical Nursing*, 12, 57-66
- Northway, R. Parker, M., Roberts, E. (2001) Collaboration in research *Nurse Researcher*, 9,2, 75-83
- O'Callaghan, N. Slevin, E. (2003) An investigation of the lived experiences of registered nurses facilitating supernumerary nursing students *Nurse Education Today* 23, 123 – 130
- Parahoo, K. Barr, O. (1996) Community mental handicap nursing services in Northern Ireland *Journal of Clinical Nursing*, 5, 4, 221 – 8
- Parahoo, K. Barr, O. McCaughan, E. (2000) Research utilisation and attitudes towards research among learning disabilities nurses in Ireland *Journal of Advanced Nursing*, 31, 3, 607 – 13
- Parley, F. (2001) Person centred outcomes: are outcomes improved where a person centred approach is used? *Journal of Learning Disabilities*, 5, 4, 299 – 308
- Parley, F. (2001) Person centred outcomes: are outcomes improved where a person centred approach is used? *Journal of Learning Disabilities*, 5, 4, 299 – 308
- Paxton, D. McKenzie, K. Dickson,K. (2001) The Screen Test *Learning Disability Practice*, 4, 2, 8 – 11

- Paxton, D. Taylor, S. (1998) Access to Primary Care for Adults with a Learning Disability *Health Bulletin*, 56, 3, 686-693
- Rawlinson, S.R. (2001) The dental and oral care needs of adults with a learning disability living in a rural community *Journal of Learning Disabilities*, 5, 2, 133 – 156
- Read, S. (2001) A year in the life of a bereavement counselling and support service for people with learning disabilities *Journal of Learning Disabilities*, 5, 1, 19-33
- Richardson, M. (1997) Participatory research methods: people with learning disabilities, *British Journal of Nursing*, 6, 19, 1114 – 21
- Richardson, M. (2000) How we live: participatory research with six people with learning difficulties *Journal of Advanced Nursing*, 32, 6, 1383 – 95
- Richardson, M. (2002) Involving people in the analysis: listening, reflecting, discounting nothing *Journal of Learning Disabilities*, 6, 1, 47 – 60
- Riding, T. (1997) Exploring values: an empirical evaluation *Journal of Learning Disabilities for Nursing, Health and Social Care*, 1, 1, 25 – 30
- Riding, T. (1997) Normalization: analysis and application within a special hospital *Journal of Psychiatric & Mental Health Nursing* 4, 1, 23-8
- Robinson, D. Whyte, L. Fidler, I. (1997) Quality of life measures in a high security environment *Nursing Standard*, 11, 49, 34 – 7
- Sawuck, G. Reeves, S. (2003) Checking violent behaviour *Learning Disability Practice*, 6, 9, 8 - 12
- Seaward, S. Rees, C. (2001) Responding to people with a learning disability who offend *Nursing Standard*, 15, 37, 36-9
- Sims, D (1999) Joint training in learning disability nursing and social work *British Journal of Community Nursing*, 4, 6, 303
- Sines, D. (1999) Identifying the need for respite care for people with learning disabilities in Northern Ireland *Journal of Learning Disabilities for Nursing, Health and Social Care*, 3, 2, 81 – 91
- Slevin, E. (1995) Student nurses' attitudes towards people with learning disabilities *British Journal of Nursing*, 4, 13, 761 – 766
- Slevin, E. McClelland, A. (1999) Multi sensory environments: are they therapeutic? A single-subject evaluation of the clinical effectiveness of a multi sensory environment *Journal of Clinical Nursing*, 8, 48 – 56

- Slevin, E. Sines, D. (1996) Attitudes of nurses in a general hospital towards people with learning disabilities: influences of contact and graduate non-graduate status a comparative study *Journal of Advanced Nursing*, 24, 6, 1116 – 26
- Slevin, E. Sines, D. (1999) Enhancing the truthfulness, consistency and transferability of a qualitative study: utilising a manifold of approaches *Nurse Researcher*, 7, 2, 79 – 97
- Slevin, E. Somerville, H. McKenna, H. (1996) The implementation and evaluation of a quality improvement initiative at Oaklands *Journal of Nursing Management*, 4, 1, 27 – 34
- Slevin, E. Lavery, I. Sines, D. (1998) Independent travel and people with learning disabilities: the view of a sample of service providers on whether this need is being met *Journal of Learning Disabilities for Nursing, Health and Social Care* 2, 4, 195 – 202
- Small, N. Pawson, N. Raghavan, R. (2003) "Choice Biography" and the importance of the social *British Journal of Learning Disabilities*, 31, 4, 159 – 165
- Smith, B. Chung, M.C. (1996) Responses and needs in a changing situation: staff who work with people with learning disability *Journal of Psychiatric & Mental Health Nursing*, 3, 3, 157-62
- Stanley, R. (1998) Primary health care provision for people with learning disabilities: a survey of general practitioners *Journal of Learning Disabilities for Nursing, Health and Social Care*, 2, 1, 23-30
- Stanley, R. Ng, J. (1998) Primary health care provision for people with learning disabilities: a survey of parents *Journal of Learning Disabilities for Nursing, Health and Social Care*, 2, 2, 71 – 8
- Stewart, D. Todd, M. (2001) Role and contribution of nurses for learning disabilities: a local study in a county of the Oxford-Anglia region *British Journal of Learning Disabilities* 29, 4, 145 – 50
- Storey, L. Dale, C. (2001) An examination of the pre-registration preparation of nurses to work in secure environments *NT Research*, 6, 4, 770- 83
- Summers, N. Jenkins, C. (2001) Enabling practice: an investigation into the support of families with children with learning disabilities *Journal of Learning Disabilities*, 5, 1, 57 – 67
- Tait, T. Beattie, A. Dejnega. (2002) Service coordination: a successful model for the delivery of multiprofessional services to children with complex needs *NT Research*, 7, 1, 19 – 32
- Turnbull, J. Timblich, D. (1998) Residential care homes: Challenges for nursing practices *Learning Disability Practice*, 1, 2, 10 – 13

Wood, P. Mason, T. (1998) Mental Impairment and Admission to a Special Hospital  
*The British Journal of Developmental Disabilities*, 44, 2, 119 - 131

## **Appendix 4**

### **International Papers Included in the Study**

- Ailey, S.H. (2000) Screening adolescents with mental retardation for depression. *Journal of School Nursing*, 16, 1, 6-11
- Bowling, M., Keltner, B.R. (1996) Primary health care for children of mothers with intellectual limitations, *Pediatric Nursing*, 22, 4, 312 - 319
- Browne, G., Bramston, P. (1996) Quality of life in the families of young people with intellectual disabilities, *Australian and New Zealand Journal of Mental Health Nursing*, 5, 120 - 130
- Browne, G., Bramston, P. (1998) Parental stress in families of young people with an intellectual disability: the nurse's role, *Australian Journal of Advanced Nursing*, 15, 3, 31-7
- Dijkstra, A., Buist, G., Dassen, T. (1996) Nursing-care dependency. Development of an assessment scale for demented and mentally handicapped patients, *Scandinavian Journal of Caring Science*, 10, 137 - 143
- Heaman, D.J. (1995) Perceived stressors and coping strategies of parents who have children with developmental disabilities: a comparison of mothers with fathers, *Journal of Pediatric Nursing*, 10 (5) 311 - 320
- Heller, T., Factor, A.R., Hsieh, K., Earle Hahn, J. (1998) Impact of age and transitions out of nursing homes for adults with developmental disabilities, *American Journal on Mental Retardation*, 103 (3) 236 - 248
- Kozma, C., Mason, S. (2003) Survey of nursing and medical profile prior to deinstitutionalization of a population with profound mental retardation, *Clinical Nursing Research*, 12, 1, 8 - 22
- Rodriguez, J.A., Jones, E.G. (1996) Foster parents' early adaptation to the placement of a child with developmental disabilities in their home, *Journal of Pediatric Nursing*, 11, 2, 111 - 117
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Her research and policy interests include disability rights and mental health and disabled people's opportunities in employment, education and health services. In 2003, the Disability Rights Commission, which supported Ms Marshall's case, is still awaiting the judgment on the substantive question of whether the risk assessment undertaken as part of the occupational health assessment was adequate. First Review of the Disability Discrimination Act 1995. London: Disability Rights Commission. 2 The Disability Discrimination Act: a does not cover people with learning disabilities b permits the NHS not to employ nurses who have received psychiatric treatment in the past 2 years c covers people with disabilities lasting more than 1.