

The research base for Learning Disability Nursing: a rapid scoping review

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Summary

Background

The needs for health and social care among people with learning disabilities are great and there are significant obstacles to equitable access to services. Nurses working across a variety of settings can be instrumental in meeting these challenges and remedying inequity. A research base that is accessible and usable by nurses must be of sufficient quality and quantity to be of value in both highlighting clients' needs and identifying effective strategies for meeting those needs.

Although much evidence for practice may be drawn from other disciplines, the UK Learning Disability Consultant Nurse Network has noted that the evidence base for learning disability nurses' clinical practice should not solely be supplied by other disciplines and specialties nor should it be exclusively inferred from evidence about the work of others.

This review aimed to scope the nature and extent of '*learning disability nursing research*' between 1996 and 2006 in order to determine whether the research base to support nursing practice is sufficient and fit for purpose.

Method of Review

Learning disability nursing research was defined as any form of systematic enquiry which concerned the work of people employed in a nursing role (whether specialist trained or not) as it impacted on or was experienced by people with learning disabilities, their carers, family members or nurses themselves. We undertook searches of the Cochrane Library, and the databases Medline, Psychinfo, Embase, CINAHL and BNI for the years 1996-2006. The core data extracted from each study was the topic and nature of research (including the groups studied and sample sizes).

Findings

We identified 175 relevant studies. Of these 124 (71%) emanated from research teams or individual researchers based within the UK or else concerned practice within the UK. Early years (from 1996 to 2000) rendered considerably fewer studies than the later years (2001 onward) although the steady year on year increase from 1996 to 2000 is not repeated in later years, with peaks of publications in 2002 (22) and 2005 (25).

Both qualitative and quantitative studies tended toward being descriptive rather than analytic. Convenience samples predominated. Typical sample sizes were small and rarely appeared to be adequate for the questions that were being addressed. Qualitative studies were as deficient in providing a rationale for the sample as quantitative studies.

Fifty-four papers were identified and classified as being primarily about people with learning disabilities and the experience or impact of nursing. Fifty five studies were classified as focusing primarily on the families or carers of people with learning disabilities. Nearly all of these studies specifically concerned parents and family carers of children with a learning disability. The largest group (Sixty-eight studies) focussed primarily on nurses or those performing a nursing role.

There are very few studies evaluating direct intervention or delivery of care by learning disability nurses and very few studies examining nurse interventions for common problems such as behavioural difficulties and an absence of strong evidence about effectiveness. There is a relatively strong theme in addressing physical and mental health care in terms of service development, assessment or client experience although the number of studies in this area is still small in absolute terms.

Few of the evaluations of interventions or service delivery utilise robust designs that are likely to provide evidence to support decisions about best ways to deliver care.

The experience of parents and family members living with a child with learning disability and interacting with services is relatively prominent as a research topic but there is little research about the impact or experience of specialist learning disability services or the experience of accessing mainstream health or social care from the perspective of parents and carers. In many studies the

contribution of nursing was implicit rather than explicit. Some service evaluation studies have been undertaken but these are mostly descriptive or qualitative explorations of meaning.

There is some preoccupation with 'theory practice gap' and educational need but little evaluation of attempts to rectify problems and few robust evaluations of interventions designed to improve nurses' skills and knowledge. There is some focus on roles but again this is primarily descriptive. The relatively strong research base on nursing careers is primarily descriptive.

Conclusions

The extent of learning disability nursing research is limited in quantity and its ability to provide reliable, generalisable or trustworthy insights. Much of what exists is fragmented and consists of small scale evaluations which may provide useful guidance and inspiration for service development but do not, in themselves, constitute robust research evidence.

The volume of research appears to be *disproportionately small* when compared to nursing research as a whole. The UK provides the majority of studies and it may be that the shortfall in volume is because there is little work conducted elsewhere, in particular the USA, which contributes a majority of nursing research in general. Limited evidence suggests that there may be less funded research than in other branches of nursing although the reason for this is unclear.

There is little evidence of sustained programmes of research and developmental cross fertilisation across research studies. Even where we noted a 'cluster' of activity, such as health needs assessment, there is a tendency to duplicate limitations of previous studies rather than undertake replication based on previous work.

We conclude that the current body of learning disability research is not fit for purpose in terms of its extent, quantity or quality.

Implications and Recommendations

For researchers and the academic community

Within the research community there should be a priority given to research aimed at determining the impact of interventions and services delivered by nurses in terms of effectiveness and the experiences of clients and carers.

The current research base suggests that areas to prioritise are mechanisms for improving access and experience of general health care and interventions for behavioural problems (or to support carers in this regard).

Given the limited resources available there should be a reduction in activity aimed at simply describing life experiences in general as other practice disciplines, and social science in general also operate within this area.

Research should be more programmatic. Individual researchers should pay close attention to recommendations of previous research and recognise the value of replication.

Given the limited resources available and the demands that research may place on participants, more attention should be given to quality in the design of studies.

Strategic alliances should be formed with cognate disciplines. This may be with the wider nursing research community or with other disciplines such as psychology or social work.

Researchers should seek out international contacts to foster further opportunities for cross fertilisation and identify potential opportunities for international collaboration. The small but significant level of activity within Europe suggests that local alliances with nurses working within socialised health systems may be possible.

Consideration should be given to *how* much of the small scale descriptive research is generated. Since much of this may emanate from student research, responsibility must rest on academic supervisors in providing guidance on topic selection.

For policy and research funders

Given the ad-hoc and apparently unfunded nature of the majority of the body of research, consideration must be given to potential infrastructures to support the recommendations made above.

Current and potential research leaders – academics, nurse consultants and others – should be identified and present capacity assessed in order to identify supportive actions to increase capacity.

Consideration should be given to strategic investments which could be used to generate critical mass. Potential options might be focussed research funding or research centres.

Introduction

In the United Kingdom a specific specialty exists in order to meet the nursing needs of people with learning disabilities that is almost unique in the world. The origins of the specialty can be traced back to the late C19th, when distinctions began to be made between '*lunatics*' and '*idiots*', with the 1886 Idiots Act making provision for the creation of mental '*idiot asylums*' and special schools. The identity of a nursing specialty was further advanced following the codification of forms of '*mental deficiency*' by the UK's Mental Deficiency Act of 1913. The act aimed to provide care and protection to those encompassed by its definitions. Consequent to this act the Medico-Psychological Association (forerunner of the Royal College of Psychiatrists) instituted a separate nursing certificate in mental deficiency nursing in 1919 (Royal College of Psychiatrists, no date), marking formal recognition of the distinct specialty which had hitherto been largely regarded entirely as an aspect of mental health nursing. Although not one of the first specialisms recorded when the general Nursing Council began to maintain a register, mental deficiency nursing under a variety of names has been part of the 'profession' since the early days of registration until the present day.

While debates about inclusion of the specialty within *nursing* have been present since the early days of registration (Mitchell, 2002), a debate which is reflected in the lack of equivalent specialties in most other countries, the recognition of the *distinctive* nature of practice is largely unquestioned. As a key group working with people with learning disabilities in a professional capacity, dealing with physical and mental health needs as well as wider social needs, there is an expectation that this distinctive element would be reflected in a research base. Debates about the professional status of the specialty are often punctuated by a reference to the significance of an accompanying research base.

However, within the 1999 strategic review of research in the UK NHS, the mental health working group identified learning disability as an underdeveloped area for research. Several authors have noted a relative lack of learning disability nursing research in particular, although sources cited in support of the proposition have not directly addressed the question or been directly supported by empirical evidence (see for example Lennox and Kerr, 1997, Parahoo et al., 2000, Wray, 1998), a point acknowledged by Parahoo (2000). The UK Learning Disability Consultant Nurse Network, in its '*Shaping the future*' report (Northway, Hutchinson et al., 2006) implicitly acknowledge an ongoing deficit in their call for a research infrastructure parallel to other professional groups noting that the evidence base for learning disability nurses' clinical practice should not solely be supplied by other disciplines and specialties.

It is in this context that this review was undertaken. The aim of the review was to scope the nature and extent of the current evidence base for learning disability nursing. At about the same time that the current work commenced, another group was completing a similar review (Northway, Mitchell et al., 2006), albeit operating within slightly different parameters including a more limited date range (1995-2003) than this review (1996-2006). Since many of the boundaries set around both these reviews are based on subjective definitions and because the consequences of particular decisions, for example on search strategies and inclusion, are unknowable without assessing the alternatives, the existence of two reviews creates an opportunity. The parallel works allow for this long-standing gap to be filled in a more robust fashion than a single review could, since the partial replication allows the robustness of the conclusions to be tested.

Methods

Scope & definition of 'learning disability nursing research'

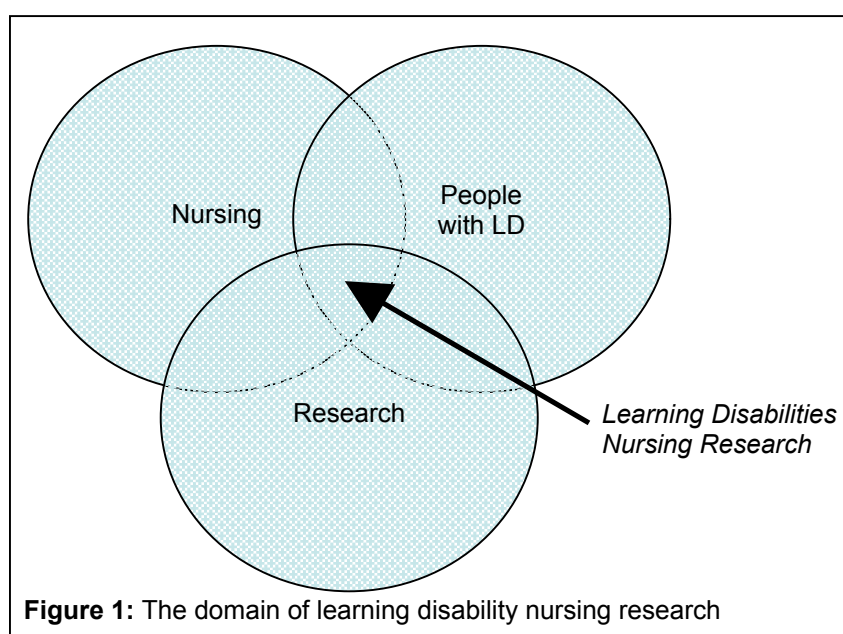
The review aimed to identify all research published in the English language between 1996 and 2006 which concerned the work of people employed in a nursing role (whether specialist trained or not) in any care setting (including the community or institutional) as it impacted on, or was experienced by, people with learning disabilities, their carers, family members or nurses themselves. We defined research as any form of systematic enquiry, including descriptive evaluations. Single case studies at the client level were excluded.

We defined learning disability in terms of the three widely recognised core criteria of significant impairment in intellectual and social/adaptive functioning with onset before adulthood (British Psychological Society, 2000) although it was generally not possible to test these definitions formally from published accounts. We accepted authors' descriptions of the populations using this or broadly synonymous terms (e.g. mental retardation) or else inferred from syndromes (e.g. Down's) that there was a learning disability. We included studies that examined the impact or experience of a service, intervention or care that is delivered by personnel identified as nurses or where there was a clear implication that there was a nursing role. For example, studies in which health screening tools for people with learning disabilities were developed were included if the potential role of nurses was identified. On the other hand a report of a screening programme would only be considered if screening had been undertaken by nurses. Studies about clients' and carers' experience of services as a whole were included where the contribution of nursing services was likely to be significant. So, for example, we included studies of the experience of hospitalization since nursing is likely to contribute much to this experience. We also included studies about the education training or experiences of nurses working with people with learning disabilities. We avoided any further precise pre-definition of 'nursing' for the purposes of the review since the applicability of generic definitions of nursing in this field is contested (Norman, 1997) and it is acknowledged that the link to the wider "family of nursing" is challenged in the current contexts of practice (Northway, Hutchinson et al., 2006). We did not wish to exclude the work of learning disability nurses if it fell outside the commonly accepted spheres but was still labelled as nursing or the staff explicitly identified as nurses.

Studies that were concerned solely with the prevalence or pathophysiology of syndromes leading to learning disabilities or of ill health among carers or nurses themselves were not considered but studies which looked at health needs among a population of people with learning disabilities were

included if they met other criteria. Finally, we did not consider studies of medical treatments (eg drug therapies) although we included studies about the impact or experience of changed roles in managing therapies, including drugs.

Our definition of 'learning disability nursing research' differs slightly from that of Northway et al's review, albeit in a nuanced fashion. Their definition locates learning disability nursing (research) as a discipline at the intersection of



nursing (research) and other cognate academic and practice disciplines (medicine, management, psychology, social policy, sociology) with learning disability nursing and learning disability nursing research operating within the same boundaries. Hence the professional identity of the researcher is also incorporated into their definition. We prefer to conceptualise the topic as the intersection between a particular form of knowledge generation (research), a field of practice (nursing) and a client group (people with learning disabilities) figure 1.

Both conceptualisations recognise that research from outside the specific field of practice, applied research from another practice discipline (for example the effect of behaviour therapy delivered by a psychologist) or non-practice research (for example sociological research on stigma) can inform learning disability nursing.

Crucially our approach differs from Northway because our definition and selection approach does not rest in any way upon the research being undertaken by nurses. Notwithstanding this decision, we recognise that the participation of learning disability nurses in developing research gives some indication of the profession's capacity to undertake research. However, we did not pursue this approach because it would depend upon the authors identifying themselves as learning disability nurses and we suspect would still require some assessment of relevance (since many nurses are dual qualified and may publish in completely unrelated topics).

Search Strategy

We undertook searches of the Cochrane Library, Medline, Psychinfo, Embase, CINAHL and BNI for the years 1996-2007 in early 2007 to ensure full coverage up to the end of 2006. All searches were conducted using the OVID platform except for the Cochrane Library. Our core search strategy was based upon terms linked to learning disability, mental handicap and developmental delay in addition to terms for common specific syndromes (see table 1). Terms were truncated as appropriate (so for example all permutations of mental, mentally and retarded, retardation were searched) and where available, index terms were used in addition free text key words.

Table 1 Search terms

Key words

learning *next to* difficulty *or* disability *or* disorder
 mental *next to* retardation *or* handicap
 developmental *next to* delay *or* disability *or* disorders
 asperger
 autism
 autistic
 down syndrome
 intellectual impairment

Index terms:

Asperger Syndrome
 Autistic Disorder
 Child Development Disorders
 Developmental Disabilities
 Down Syndrome
 Learning Disorders
 Mental Retardation

On non-nursing databases (i.e. all except CINAHL and BNI) the subject search also incorporated terms for nurse, nurses nursing and index terms for mental health, school and community nursing specialists. These were used to limit (Boolean AND) the core search.

All searches were further limited (see appendix) in order to make the results specific for research using searches designed by the Health Information Research Unit (HIRU) at McMaster University (HIRU, no date) to identify a variety of research designs for studies of [therapy](#), [diagnosis](#), [prognosis](#), [economics](#), [cost](#), [clinical prediction guides](#) and [qualitative](#) research. We also used limits available within the databases for research studies. Citations were retained if they matched on ANY of our limits. Thus we aimed to improve the sensitivity of our

search results for research while minimising the loss of sensitivity. We also limited our search to editorial board or peer reviewed journals and publications in the English language as research is much more likely to be published within these journals.

We undertook limited scrutiny of reference lists but did not conduct any author or citation searching. Nor did we undertake hand searching of key journals due to limited time and resources.

Study selection

We developed a proforma for selecting relevant studies based upon our scope and definition (*above*). The proforma was also used to classify whether the focus of the research was people with learning disability, carers / relatives of people with or nurses working with people with learning disability.

Where several groups were involved the paper would be classified as relating to people with learning disabilities if it included both them and carers. A study would only be classified as being about nurses if neither people with learning disabilities or carers were involved. Selection against these criteria was tested by 2 reviewers independently rating a sample of 20 papers of a variety of research types and topics including equal numbers of studies rated by the first reviewer as included and excluded. Agreement was high (80 %+) and consensus easy to reach regarding the remainder, which allowed clarification and refinement of the proforma. Subsequently this proforma was used to liberally screen all studies (primarily based upon title and abstract) and to allocate the study to one of the three categories. The resulting three groups of studies were then allocated to a single reviewer who further selected and extracted study descriptions of those included. Reviewers met and discussed where there was uncertainty and passed misclassified studies to the appropriate reviewer.

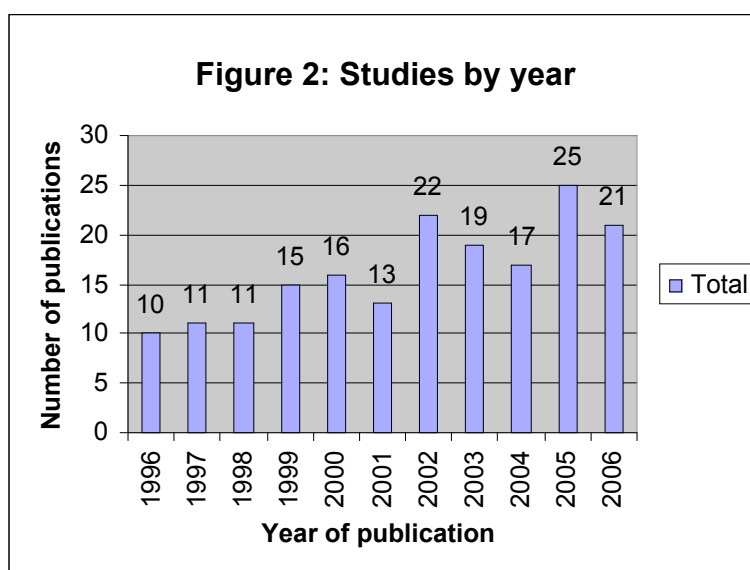
Analysis

Once allocated to a major review section individual reviewers categorised and sorted studies into themed groupings based primarily on information from the abstract. Judgements were made on the basis of a perception of the main contribution of a particular study which was not always based upon the study topic. Thus a study on inter-professional education might enter a section on pre-registration education because of its recommendations related to that topic while other studies on inter-professional working would enter a section on roles of learning disability nurses because the major focus was the role of learning disability nurses within the team. Often a study could reasonably be entered under more than one theme although in general this was avoided. There was no formal validation of the themes arrived at by individual reviewers and judgement about placement was largely subjective. One reviewer collated all the findings sections and thus provided informal validation of the judgement of others, although changes to categorisation were only made where misclassification was gross. The core data extracted from each study was the topic and nature of research including the groups studied and sample sizes. As we did not formally appraise the quality of each individual study or the extent to which conclusions were supported by findings we have avoided reporting these elements. Instead the synthesis is descriptive of the research topics and approaches.

Findings

Introduction

Initial searches yielded 827 references of which 284 were retained after liberal screening and 175 finally identified as relevant. A further five studies were identified following feedback from reviewers of a draft of this report making 180 studies in all. Of these 129 (72%) emanated from research teams or individual researchers based in or else concerned practice within the UK. Early years (from 1996 to 2000) rendered considerably fewer studies than the later years (2001 onward) although the upward trend from 1996 to 2000 is not consistently repeated in later years with peaks of publications in 2002 (22) and 2005 (25).



We did not formally scrutinise the quality of all the research in detail. Where we did assess the quality of individual studies in depth we found that reporting of methods was often weak. Few, if any, studies complied with emerging consensus standards for reporting research that have emerged as part of the evidence based-practice movement since the publication of the CONSORT guidelines (Altman, 1996) even though these exist for many of the designs reported including non-randomised evaluations (Des Jarlais et al., 2004) and qualitative research (Elliott et al., 1999). Strong designs had often not been utilised even where

appropriate. Both qualitative and quantitative studies tended toward being descriptive rather than analytic. Convenience samples predominated. Typical sample sizes were small and rarely appeared to be adequate for the questions that were being addressed. Qualitative studies, where small sample sizes might be acceptable, were as deficient in providing a rationale for the sample as quantitative studies. Clearly recruitment of sufficient research participants was often a major issue and many evaluations utilised all available and willing candidates. However, even in studies where the issue was less apparent, sample size was frequently deficient or not considered.

We now consider the content of the research in more detail within our three broad categories – research about people with learning disabilities themselves, research about carers and relatives and research about nurses. The distinction is, in many cases, arbitrary but the key determinant is who the data is collected from or whose experience it is based upon. In general research cited is UK based unless otherwise specified.

Research about people with learning disabilities

Introduction

Fifty-six papers were identified and classified as being primarily about people with learning disabilities and the experience or impact of nursing. Within this group UK based research was by far the largest group (65%) with research from the USA forming the next largest group (19%). In many cases the research has been retained for consideration because of the implicit involvement of nurses within an overall service (for example the experience of patients in hospital). In part because of the implicit nursing role and partly because of the international diversity of the literature, specialist learning disability nursing is explicitly identified as part of the services described or evaluated in only 29% of the research.

The literature been grouped according to a number of broad themes:

- ☐ Studies to evaluate the effect of service development or interventions
- ☐ Studies to assess the prevalence of need
- ☐ Studies to develop assessment mechanisms and scales
- ☐ Studies to explore the experience of a service or services as a whole

The effect of service development or interventions

We identified 25 studies that evaluated the effect of service development or nursing interventions. The largest group of these (12) described the impact of services designed to improve the general health care of people with learning disability, typically by means of a screening programme. Often these programmes involved providing feedback on risks and advice to clients and carers. For example the 'Stay Well and Healthy!' programme in the USA (Aronow and Hahn, 2005) or the UK's 'Health watch' (Kerr et al., 2003) in which assessments of health risk were followed up with tailored advice to clients / carers. Some similar UK work has involved integrated teams within primary care, including specialist community learning disability nurses (Cassidy et al., 2002, Cooper et al., 2006, Martin, 2003, Martin et al., 2004) who undertook reviews of records and physical assessments with follow-up care recommendations made to the GP and referral to other specialists made by the nurse. While most of the programmes were general, some focussed on mental health (Roy et al., 1997) or specific syndromes such as obesity (Marshall, McConkey et al., 2003). A related group of work (3 studies) focuses on the provision of enhanced access to services (Allan, 1997, Scott et al., 2005) or a service targeted at a risk factor rather than screening and risk assessment per se although much of this, such as the provision of a personal health resource (Scott et al., 2005, Tohill and Lavery, 2001) overlap considerably with the previous group and the distinction is often based on the nuances applied by the author. A further study evaluated the quality of primary care provision for people with learning disabilities (Plant, 1997), one (Hannon, 2004) a service to enhance the quality of general hospital care through pre-admission assessment by a learning disability nurse and an overall evaluation of the community learning disability nursing service (Koch et al., 2001).

The remaining studies were disparate. A small group of studies examined various behaviour management interventions in a variety of settings including a Canadian Rehabilitation centre (Mate-Kole et al., 1999) a UK forensic psychiatry setting (Burns et al., 2003) children in the community (Gates et al., 2001) and an inpatient unit in Hong Kong (To and Chan, 2000). A single study examined community support teams for people with learning disabilities and challenging behaviour (Emerson, 1996) in a national survey. Topics covered in other studies were the impact of a quality improvement programme for learning disability nurses in a children's centre (Slevin et al., 1996), the relationship between case mix and violence in forensic inpatient settings (LePage et al., 2005), the provision of spiritual support (Swinton, 2002), decision making about risk by Dutch nurses caring for people with epilepsy (Vallenga et al., 2006), training to improve client understanding about confidentiality (McKenzie et al., 2002).

The most common design used (45%) was a simple 'before and after' where the status before the intervention is compared to that afterwards. This has little explanatory power and the ability to attribute cause to the intervention described is inevitably low. Most other studies (33%) took a purely descriptive approach to evaluation utilising either survey or qualitative approaches. Only four studies (17%) utilised some form of controlled comparison with one using randomisation to form a comparison group. Typically studies had samples within the range of 20-50 participants. Some studies included very few people with learning disabilities (the lowest was 3) although sometimes these accounts were supplemented by those of carers. Only six studies (24%) had samples of 100 or more with the largest (Emerson, 1996) including data from 1200 people served by thirty five teams.

The prevalence of need

Eleven studies were classified as primarily addressing the prevalence of health need among people with learning disabilities. Clearly these represent only a small minority of the literature on health needs in these populations but entered this review primarily because of the involvement of a nursing service in determining or potentially meeting the need that was explicit in the study. Of these studies, six addressed broad general health needs (Barr et al., 1999, Betz et al., 2003, Goldsmith et al., 2000,

Mahon and Kibirige, 2004, Thompson et al., 1999) in varying populations including both children (Thompson et al., 1999) a general practice population (Goldsmith et al., 2000) and children with special needs admitted to hospital (Mahon and Kibirige, 2004). Of these studies one was conducted in the USA (Betz et al., 2003) and the other in the republic of Ireland (McCarron et al., 2005). A further study examined the mental health needs of people with learning disability in police custody (Scott et al., 2006). Other studies took a narrower focus and generally examined informational needs in relation to particular conditions or health risks such as cancer (Davies and Duff, 2001, Tuffrey-Wijne et al., 2006) smoking (Taylor et al., 2004) or sexual health among people with learning disabilities in the USA (Brown and Jemmott, 2002).

The majority of studies consisted of small surveys, with as few as seven people with learning disabilities involved, conducted on specific and potentially unrepresentative populations. Two surveys (Scott et al., 2006, Taylor et al., 2004) had large samples (1000+, 400+) and the potential to provide robust estimates in the population. Of the qualitative studies (Brown and Jemmott, 2002) had a potentially robust sample (15 people with learning disabilities or carers in addition to professionals) while (Tuffrey-Wijne et al., 2006) had a sample of only 5, which is unlikely to be adequate for anything other than highly in depth enquiry such as phenomenology, which this is not.

Assessment mechanisms and scale

Eight studies were identified which examined the development or validation of assessment methods for nursing or when conducted by nurses. Of these, three (Ailey, 2000, Evans et al., 1999, Moss et al., 1998) were assessments of mental health status with a further study (Olsson and Wambold, 2003) examining the reliability and validity of a screen for cognitive decline / dementia in people with Down Syndrome. Of these studies only (Moss et al., 1998) was conducted in the UK. Two surveys explored the assessment of pain by nurses (Fanurik et al., 1998, Zwakhalen et al., 2004), one described the development of a care dependency scale (Dijkstra et al., 2000), one an assessment for injury risk (Konarski and Tasse, 2005) and one the reliability of a nutrition screen when used by nurses (Bryan et al., 1998) which was the only other study in this section conducted in the UK.

Studies generally had larger and potentially more adequate sample sizes than noted in previous sections. The smallest study (Ailey, 2000) was a scale validation with only 27 participants but typically sample sizes were greater with most having more than 100 while Moss Prosser's validation of the PAS-ADD depression scale had over 200 participants (Moss et al., 1998). Some of these studies were limited and in particular there was rarely reference to a gold standard in validation of diagnostic / screening assessments although generally there was some reference to an external criterion for determining validity.

The experience of a service or services as a whole

Twelve studies reported experiences of services. There is potential overlap between this section and some of the descriptive evaluations above. However, the distinction was generally based upon the authors stated intent to focus on client experience as opposed to evaluate a service per se. Of the 12 studies six focussed on experiences of general health care services, either physical health settings in the UK (Broughton and Thomson, 2000) or USA (Kopac et al., 1998, Pulcini et al., 1999) or mental health settings in the UK. Of the four physical health care studies three concerned women's experiences relating to gynaecological care (Broughton and Thomson, 2000, Kopac et al., 1998, Pulcini et al., 1999) the other with the experience of hospital admission (Hart, 1998). The two studies in mental health settings focussed on experience of violence or bullying in inpatient units (Chaplin et al., 2006, Sasse and Gough, 2005). In addition, two studies concerned experiences of physical health interventions or states. One study examined laxative use in Dutch residential settings (Van Winckel et al., 1999) and the pain experience of American children with learning disabilities (Malviya et al., 2001). Two studies described experiences of interventions for challenging behaviours (Lovell, 2004) in the UK and (Saloviita, 2002) in Finland. One study gave a general account of life experiences including perceptions of nursing and one described practices around discussions of death and dying (Todd, 2004).

Sample sizes among the seven qualitative studies ranged from six to 127 while the surveys included samples from 19 to 460. The smallest of the qualitative studies *"How We Live"* (Richardson, 2000)

aspired to in-depth exploration making the small sample acceptable. In general the studies in this section were not so clearly deficient in their sample sizes as many observed in other sections.

Summary points

- Overall there is a low number of evaluations of interventions or service delivery with very few utilising robust designs that are likely to provide evidence to support decisions about best ways to deliver care
- There are very few studies evaluating direct intervention or delivery of care by learning disability nurses
- There are very few studies examining nurse interventions for common problems such as behavioural difficulties and an absence of strong evidence about effectiveness
- There is a relatively strong theme in addressing physical and mental health care in terms of service development, assessment or client experience although the number of studies in this area is still small in absolute terms
- There is some focus on specific areas such as gynaecological examination and mental health.

Research about families and carers

Introduction

Fifty five studies were classified as focusing primarily on the families or carers of people with learning disabilities. Nearly all of the papers specifically concerned parents and family carers of children with a learning disability (46); others focused on the experiences of siblings (7), grandparents (1), and fosterers (1). As in the previous section a majority of the literature (55%) emanates from the UK but it is by no means overwhelming with the USA providing the second largest group of studies (24%). Although most of this literature does not directly relate to nursing interventions or nursing care, it provides valuable information about the support needs of people with learning disabilities and their families. The inclusion of many of these studies was based on the explicit consideration of the implications for nursing practice by the authors or the significance of health services in shaping the services emerging as a finding. The literature has been grouped into the following themes:

- ☐ Being a parent of a child with a learning disability
- ☐ Wider family and family structures
- ☐ Cultural and social responses
- ☐ Family self-care and self-agency
- ☐ Family-centred service development
- ☐ Experiences of respite and residential placements

Being a parent of a child with a learning disability

We found eight studies concerned primarily with the experience of being a parent of a child with a learning disability. Generally mothers are considered to be the primary carers of children with learning disability. Research has conveyed mothers' perspectives about the meaning of mothering (Shu et al., 2001) and self-identity (Shu et al., 2006). Some studies examined maternal stress and depression (Buelow et al., 2006) while others examined experiences of distress and sorrow (Mallow and Bechtel, 1999). One study explored the impact of a support intervention on psychological well-being (Shu and Lung, 2005). One study included fathers' experiences of parenting (Catherall and Iphofen, 2006) while another focused on the meaning of fathering in relation to a child with learning disability specifically (Baumann and Braddick, 1999). One study compared mothers and fathers in terms of communication strategies (Pelchat et al., 2003).

The methods used were mainly qualitative approaches, often involving focus groups, to explore issues in-depth. Sample sizes were generally small with the average being 10-15 parents. Sample sizes were rarely justified. One study (Shu and Lung, 2005) used a quasi experimental approach with a total sample of 48. Controls were self selected based on willingness to participate and so the explanatory power of the study was low.

Wider family and family structures

The experiences of carers and family members other than parents were examined in nine studies. Seven considered siblings of children with learning disabilities. Research has looked at issues to do with an elder brother or sister being cared for in a residential placement (Conway and O'Neill, 2004) and the views of siblings on professional attitudes and their interactions with health professionals (Faux and Seideman, 1996). One study explored younger sibling's experiences of family dynamics and coping strategies (Van Riper, 1999). Research from Sweden (Andersson, 1997) examined siblings adaptation to change in the family. Other research (Hodapp et al., 1997) compared parental perceptions of sibling experience with that of the sibling and other research on the complexity of the sibling's experience (Baumann et al., 2005). One study used parental report to identify the rates of assaults by siblings on children with Asperger's syndrome on non-verbal learning disorders (Little, 2002).

One study focussed on the role and experiences of grandparents in providing care and support within families (Katz and Kessel, 2002). A single study related to the experience of foster parents (Rodriguez and Jones, 1996).

Again qualitative methods predominated with sample sizes generally in the range of 10-15. One was a secondary analysis of a large qualitative dataset obtained from 72 families (Andersson, 1997). This section also included a number of questionnaire surveys with sample sizes of 89 (Van Riper, 1999) to over 400 (Little, 2002).

Cultural and social responses

The theme of beliefs and culture specific responses in relation to caring for people with learning disabilities was raised in nine studies. One study examined correlations between experiences of isolation and the influence of cultural beliefs within different communities in the UK (Gatford, 2001) while another explored parental beliefs in order to inform nurse delivered education for parents and correct 'errors' (Elder, 2001). Qualitative studies undertaken internationally identify specific cultural factors impacting upon the experience of carers in Hong Kong (Lam and Mackenzie, 2002), Lebanon (Azar and Badr, 2006) and the United States where spiritual belief and religious support among families was examined (Marshall, Olsen et al., 2003).

A number of studies have examined the emotional landscape of parents. One study contrasted societal and professional assumptions of parental crisis and maladjustment in response to having a disabled child with professional's experience of working with families (Kearney and Griffin, 2001). One study contrasted mothers and fathers emotional response and identified the impact of services on mother's responses (Mallow and Bechtel, 1999), another (Rehm and Bradley, 2005a) examined the process of 'normalization' while a final study examined the 'prevalent joys' and concerns of parenting (Little and Clark, 2006).

All but one of the studies were qualitative with most having small samples. Two qualitative studies had unusually large samples of 40 or more (Elder, 2001, Little and Clark, 2006). One of these utilised written responses from a survey that recruited 104 parents via an internet site for parents of children with learning disability (Little and Clark, 2006) raising questions about the typicality of participants. The single quantitative study had a sample of 127 (Azar and Badr, 2006) but it is unclear if this is representative of the population.

Family self-care and self-agency

Fifteen studies were identified that considered family self-efficacy and self agency and issues around coping with the delivery of enhanced support to a relative with a learning disability. Five studies sought to identify and explore parental coping strategies, such as the search for social safety, information and comfort and support in families (Rehm and Bradley, 2005b, Taanila et al., 2002) resiliency (Van Riper, 2000) and parent's beliefs and responses concerning diagnosis, cause, and utilisation of medical and complementary care (Harrington et al., 2006). One study examined the relationship between social support provided by nurse practitioners and self-care agency of mothers of children with developmental disabilities (Beauchesne, 1997).

Seven studies have evaluated training programmes for family members such as interventions for parental support (Shu and Lung, 2005), behaviour management (Shinnick and McDonnell, 2003, Williams-Jones and Catherall, 2004), and child development (Elder et al., 2003, Elder et al., 2005).

Two studies examined the meaning and experience of touch between parent and child (Cullen and Barlow, 2002, Cullen et al., 2005). A subsequent exploratory study (Cullen-Powell et al., 2005) examined the impact of a massage intervention upon the emotional reactions of parents. Other studies examined parents' feelings about delivering personal intimate care (Clark, 2006) and feelings about sexuality among carers in Ireland (Drummond, 2006).

The studies in this questions included two studies (Elder et al., 2003, Shinnick and McDonnell, 2003) based on in-depth analysis of very small numbers (4 and 2 respectively). Many of the rest of the studies were qualitative studies with modest sample sizes and included two evaluations of service innovations (Cullen and Barlow, 2002, Williams-Jones and Catherall, 2004). Three studies were before and after evaluations of interventions (Cullen-Powell et al., 2005, Elder et al., 2003, Elder et al., 2005, Shinnick and McDonnell, 2003) and one a quasi experiment with control (Shu and Lung, 2005). With sample sizes of less than 50 and lack of control in these studies it is difficult to make any causal attribution difficult although the focus on parental perceptions of many means that some useful results can be gleaned.

Family-centred service development

Thirteen studies explored measures and instruments for the assessment of need. One study examined the reliability and validity of an instrument offers designed identify and measuring care and resources requirements (CAS-ID) (McCarron et al., 2002). A single study examined the impact of dual diagnosis (i.e. intellectual disability and mental disorder) on carers (McIntyre et al., 2002). In the United States changes over time in service utilisation by parents were evaluated (Miltiades and Pruchno, 2001).

A number of studies explored carers views and experiences of service provision with a focus on nursing services (Manthorpe et al., 2003) or potential demand for specialist nursing support (Davies, 1996). One study explored how professionals can best act as a support to parents (Lindblad et al., 2005).

A number of studies examined parental evaluation of services. These focussed on broad learning disability service developments (Appleton et al., 1997), the effect of interventions to support parents after 'diagnosis' (Giarelli et al., 2005) and experience of health care mainstream health care provision (Chell, 2006, Fox and Wilson, 1999). Other studies relate to parent's experiences of transitional care for adolescents in the USA (Betz et al., 2004). Other research from the United States explored factors that influenced interactions between parents and health professionals (Faux and Seideman, 1996) a topic also explored in the UK (Watson et al., 2006).

Like other sections this one included a high proportion of small qualitative studies although it is more diverse with one grounded theory study with a relatively large (34) number of participants (Watson et al., 2006), some relatively large surveys with samples of up to 300 (Betz et al., 2004, Davies, 1996, McIntyre et al., 2002, Miltiades and Pruchno, 2001) and a small (31) randomised controlled trial (Giarelli et al., 2005). The size of the controlled trial is such that few if any conclusions can be drawn about service effectiveness.

Experiences of respite and residential placements

Nine studies examined carers' perspectives and experiences of respite or residential care placements. Four studies explored issues and concerns of parents associated with deciding whether to access respite care (Catherall and Iphofen, 2006, Davies, 1996, Hartrey and Wells, 2003, Treneman et al., 1997). Another four papers addressed specific issues to do with accessing residential placements (Conway and O'Neill, 2004, Freedman et al., 1997, Miltiades and Pruchno, 2001, Wong and Wong, 2003) and a further study explored residential plans by parents of adults with learning disabilities (Freedman et al., 1997).

Like the previous section small qualitative studies remain predominant but this section also includes four surveys (Davies, 1996, Freedman et al., 1997, Miltiades and Pruchno, 2001, Wong and Wong, 2003) of which three had samples of over 300 and one a sample of 1200 (Treneman et al., 1997)

Summary points

- The experience of parents and family members living with a child with learning disability and interacting with services is relatively prominent as a research topic
- The nursing role and contribution to the support or experiences of carers is not strongly reflected by research
- In many studies the contribution of nursing was implicit rather than explicit
- There is little research about the impact or experience of specialist learning disability services or the experience of accessing mainstream health or social care from the perspective of parents and carers.
- Some service evaluation studies have been undertaken but these are mostly descriptive or qualitative explorations of meaning.

Research about nurses

Introduction

Seventy-one studies were identified as focusing primarily on nurses or those performing a nursing role. In common with the other sections of this review the majority (74 %) of studies emanated from the UK. The fact that this majority is higher than the other sections no doubt reflects the existence of the specialty within UK nursing which thus renders nurses working with people with nursing disabilities a more visible and distinct group. The studies have been grouped into the following themes:

- ☐ Nursing practice and service delivery
- ☐ Education and training
- ☐ Roles within learning disability nursing
- ☐ Career

Nursing practice and service delivery

Twenty-nine studies on nursing practice and service delivery were found. The three main research topics were the challenging behaviour of people with learning disabilities, management of health problems and the communication strategies of staff working with people with learning disabilities, including verbal and non-verbal communication.

A single study examined the prevalence of challenging behaviour in learning disability nurses caseloads (Slevin, 2004). One study identified factors associated with violent incidents (Chaplin et al., 2006). Two studies, one Scandinavian (Hellzen et al., 2004), one UK based (Wanless and Jahoda, 2002), explored emotional responses and experiences of challenging behaviour and violence as among nurses working with people with learning disabilities while another explored staff's understanding and attitudes towards women's violent behaviour. One study explored attitudes of general nurses and explored beliefs about challenging behaviours (Slevin and Sines, 1996). Four studies (Azar and Badr, 2006, Bakken and Smeby, 2004, Hastings, 1996, McKenzie et al., 2006) explored strategies deployed in managing challenges, including adherence to guidelines and one (Taggart and McConkey, 2001) examined assessment strategies. Again, one of these (Bakken and Smeby, 2004) was from Scandinavia. One study examined the availability of staff to deliver services within the UK (Messent, 2003) while a further study developed a grounded theory of the work of learning disability nurse specialists who work with people who challenge (Slevin and Sines, 2005). A single study (Durnin and Freeman, 2005) examined the impact of training programme on staff.

Five papers explored the communication between those in a nursing capacity and people with learning disabilities. An observational study explored factors affecting the frequency and content of interactions between clients and health care assistants (Chan and Yau, 2002) while one study explored the frequency and nature of touching used by nurses (Gale and Hegarty, 2000). One study explored how nurses addressed spiritual needs (Narayanasamy et al., 2002). Two studies explored strategies for improving communication with clients. One evaluated the impact of training by speech and language therapists for nursing and support staff (Chatterton, 1999) and one a project to support volunteer workers within a unit for adults with profound learning disabilities (Dobson et al., 1998).

Seven studies explored nurses' management of health problems. Three studies explored nurse's knowledge and understanding of common health problems in people with learning disabilities. Two explored nurses ability to assess pain (Donovan, 2002, Fanurik et al., 1999) and one mental health problems (Munden and Perry, 2002). One study explored the content amount of teaching about pain in the learning disability curriculum (Twycross, 2000). One study examined attitudes and knowledge about care of people with learning disability among nurses in emergency departments (Sowney and Barr, 2006). Two studies examined the management of health problems by nurses in schools. One explored the work of paediatric nurses in a special school (Moore et al., 2003) while another attempted to identify the nursing skill mix for meeting health needs in special schools (Branford et al., 1997).

Other studies included an exploration of the changes to nursing practice following care in the community (Smith and Chung, 1996), two studies which explored decision making (Fisher et al., 2005, Walker et al., 2003) a single study that explored staff views of the role of occupational therapy (Adams, 2000).

The studies concerning challenging behaviour were mainly qualitative with small sample sizes. Studies about communication health care generally employed observation methodology although some focus groups were also utilised. Sample sizes again were relatively small ranging from 2 to 30 participants.

Education and training

Twenty studies concerned nurse education and training. Ten studies explored aspects of the 'theory practice' gap and the educational needs of nursing staff. One study (Parahoo et al., 2000) examined research utilisation by learning disability nurses. One study explored attitudes of care staff to behaviour modifications programmes in order to determine why implementation was often unsuccessful (Whitworth et al., 1999). Staff views of the implications of closure of psychiatric and mental handicap hospitals and the subsequent emphasis on community rather than hospital care were studied by Norman (1998) in order to identify training and support needs. Six studies examined knowledge and skills of learning disability nurses in relation to specific conditions or situations including the management and care of the terminally ill in residential settings (Ng and Li, 2003) psychosis (Isherwood et al., 2006), Alzheimer's disease (Donnelly and Earnshaw, 2002), parenting (Culley and Genders, 1999, Wharton et al., 2005), the needs of black and ethnic minority clients (Hebblethwaite et al., 2006). Of these three, (Donnelly and Earnshaw, 2002, Hebblethwaite et al., 2006, Wharton et al., 2005) included evaluations of programmes designed to improve knowledge or practice. In addition, Miers et al explored a training scheme for unqualified staff (2005).

Six studies explored aspects of pre-registration training. Three studies examined practice learning environments and support. Brown et al. (1998) explored the ideal role of a clinical tutor from the perspective of trained nurses and students. Another study explored the contact time between student nurses and people with learning disability during training (Bernal, 2004) while a further study explored student views of the benefits of clinical placements during training (Hardyman and Robinson, 2001). Twycross et al. (2000) explored teaching about pain across all UK pre-registration nursing branches, including learning disabilities. Manthorpe et al (2004) examined multi-disciplinary and multi-agency working education and practice for learning disability nurses, while other research examined a dual training programme (Etchells et al., 1999).

Four studies explored attitudes, knowledge and skills of general nurses and other staff toward delivering care to people with learning disabilities. Of these, two described attitudes in the UK (McConkey and Truesdale, 2000) and USA (Gaugler, 2005), one explored variation in attitudes

between graduates of Bachelors and Diploma programmes in the UK (Slevin and Sines, 1996) and one the impact of a programme designed to improve attitudes, knowledge and skills of children's nurses (Katz and Hayout, 2002).

Most of the studies were descriptive and based on semi-structured interviews or focus groups, a few employed documentary analysis in part or were evaluation studies, while the rest used qualitative methods. Apart from one large scale questionnaire study (McConkey and Truesdale, 2000) with a sample of over 1000, samples were in the main small.

Roles within learning disability nursing

A total of seventeen papers examined 'roles' within learning disability nursing. Two related studies looked at the roles and working practices of learning disability nurses in the community and their evolution over time (Barr, 2006, Parahoo and Barr, 1996). Eleven studies examined the role of learning disabilities in the interdisciplinary working environment. Four studies explored the role of the learning disability nurse within the multi-disciplinary working environment in general (Lacey, 1998, McCray, 2003a, McCray, 2003b, McCray and Carter, 2002). One specifically looked at the relationship between nurses and speech and language therapists (Dobson et al., 2000). Six studies explored roles in the community and primary care. Of these, four examined primary health care team's views and understanding of the needs of clients with learning disabilities and their roles in meeting them (Holloway, 2004, Melville et al., 2005, Thornton, 1996, Thornton, 1997). Two studies explored the role of community learning disability nurses from the point of view of the nurses themselves (Boarder, 2002) or the rest of the team (Powell et al., 2004).

Two studies explored the relationship between professional and managerial conceptions of role in the construction of professional trust (Gilbert, 2005a, Gilbert, 2005b). One study examined the relationship between role clarity, perception of the organisation and occupational stress among care workers in residential settings (Blumenthal et al., 1998) and one Dutch study examined the factors related to burnout and mental illness among nurses working with people with severe behaviour problems (Gerits et al., 2004).

The majority were qualitative studies employing small sample sizes. There were two quantitative studies employing relatively large sample sizes ranging up to 380 respondents (Gerits et al., 2004, Melville et al., 2005).

Career

Eight studies examined aspects of career and career development. These focused on job satisfaction (Boarder, 2002, Boumans and van den Berg, 2000, Chung and Corbett, 1998, Robinson and Murrells, 2005), career guidance (Marsland, 2001), continual professional development (Desousa and Robinson, 2002) and supervision (Davey et al., 2006, Dychawy-Rosner et al., 2000, Malin, 2000).

Generally these studies had relatively large sample sizes (up to 1900) and many were longitudinal although the numbers of learning disability nurses within the larger studies of careers were often relatively small.

Summary points

- There is some similarity to topic areas identified in the first section on people with learning disability: physical health plus a larger amount on challenging behaviour
- There is attention paid to the 'theory practice gap' and educational need but little evaluation of attempts to rectify problems
- There are few robust evaluations of interventions designed to improve nurses skills and knowledge
- There is some focus on roles but again this is primarily descriptive
- The relatively strong research base on nursing careers is primarily descriptive.

Discussion and conclusions

Overview

We found 180 papers published in the eleven years 1996-2006. Indexing of 2006 may not have been quite complete at the time of the searches but even if this is regarded as a ten year period the average number would be below 18 studies per year. Although the volume of publications has increased over the period there is no clear upward trend since 2001 and the peak year of publication, 2005, only yielded 25 studies.

The extent of the research base is small but the specialty of learning disability nursing is a small one. Of 682,220 nurses on the UK register only 20,197 (less than 3%) are learning disability nurses (source Nursing and Midwifery Council Statistical analysis of the register 2005-2006). It is hard to judge whether the contribution of learning disability nursing research is proportionate, as any comparable endeavour for 'nursing research' would be unmanageable. A crude indication of the volume of activity can be had by examining the results of our searches before joining the 'nursing' terms to those for learning disability. As an example, in our Medline searches the terms for nursing yielded 159,790 hits which reduced to 1125 after adding terms for learning disability. Similar proportions were found on Embase 441 / 42,395. In both cases the proportion is under 1%. Our review took a more inclusive approach to international research than that of Northway. It is thus all the more striking that UK studies predominate with no *multinational* research identified whatsoever.

The topics addressed are diverse but the evidence base is characterised by its overwhelmingly descriptive nature and small scale. Northway et al noted the relative balance between qualitative and quantitative methods. More striking to us is the preponderance of small scale descriptive research of both types. A sound research base that is accessible and usable by nurses must be of value in both highlighting need and identifying effective strategies for meeting it. The current research base goes some way to establishing the needs and describing the experience of clients but offers little evidence regarding strategies for intervening. The descriptive evaluations and small scale qualitative research may provide useful guidance and inspiration for service development but do not, in themselves, constitute robust research evidence and it is hard to differentiate some from well researched journalistic reports of service development. Insights into the experiences of clients and carers can be informative (although the reporting of research is such that the trustworthiness of accounts is hard to assess) and lead to changes in practice but do not provide robust evidence to guide assessments of the effect of response by practitioners. Where attempts have been made to assess the impact of services the approaches chosen have rendered the generalisability of findings very low. Ultimately relatively little of the research was about practice and in particular evidence concerning interventions by learning disability nursing was scant.

Two areas of focus were worth remarking upon. One was the relative strength of research which reflects the role of the learning disability nurse mediating between the person with learning disability and general health care services. This is reflected in research on assessment of health needs and experiences of general care settings as well as some on the effect of the provision of enhanced services designed to improve access to care. It may be that the focus on mediating relationships with health services reflects a positively determined distinctive role. Alternatively it may reflect a residual medical model in care. Within the area of health care the relatively narrow focus of topics, such as gynaecological examination for example, may reflect highest priorities but on the other hand the sum of the evidence base is unlikely, in itself, to be adequate to support practice.

The other striking element was the relative lack of studies on other interventions delivered by learning disability nurses themselves. While referral coordination and liaison may be a crucially important role, it is surprising that the active therapeutic role of learning disability nurses is not reflected in the research as this is where one might expect '*learning disability nursing research*' to focus its endeavours. Instead the impression could be gained that it is somewhat peripheral. Northway et al noted *Challenging behaviour* as a relatively strong theme within the research whereas we are inclined to regard it as a weak one (Northway, Mitchell et al., 2006). The difference is perhaps one of

perception since the absolute numbers involved are low. Northway identified 18 studies few of which evaluated interventions. The overall number is small in both reviews and little of the research on the topic reported in either review reports on the effects of services delivered by learning disability nurses on supporting or improving client behaviour or the efforts of carers to do so.

The virtual absence of robust evaluation of interventions for widely identified problems, for example in behaviour management, may reflect heavy reliance on other disciplines for provision of therapy or evidence about therapy. It is worth recapitulating the UK Learning Disability Consultant Nurse Network's '*Shaping the future*' report (Northway, Hutchinson et al., 2006) which noted that the evidence base for learning disability nurses' clinical practice should not solely be supplied by other disciplines and specialties.

The limited scope and volume of research may reflect limited funding opportunities. Learning disability nursing occupies an ambiguous space between health and social care and it may be that this ambiguity limits access to the relatively large resource for health research and the more limited funds for social care research. We did not examine research funding but Northway and colleagues did consider it. Information on funding was limited in reports with fewer than 8% identifying a funding source (Northway, Mitchell et al., 2006). By contrast a review of nursing research as a whole (Rafferty and Traynor, 2000) found that 27% of studies reported funding. It is notable that only 4/12 received funding from 'health' sources with the largest source of funding being national nursing boards 6/12. It is unclear if it is the availability of funds or the quality of the research that sets the limit.

With such a restricted base there is limited opportunity for programmes of research and cross fertilisation across topics. It would seem there are relatively few focal areas which emerge. Northway et al also noted the lack of sustained research programmes and failure to follow-up on recommendations for future research. They also noted that in some areas where we have identified a 'cluster' of activity, such as health needs assessment, there is a tendency to duplicate rather than replicate. By this they mean that rather than building on existing research, the limits of earlier research are repeated with minor alterations in the approaches evaluated limiting progress.

Limitations

Although we found more material overall, this is largely due to the increased range of years. Our review identified 116 studies in the years 1996-2003 while Northway identified 152. However, our search strategy would tend to 'bias' our results toward higher quality and most specifically peer reviewed journals. Importantly our approach more clearly replicates the activity of a practitioner actively searching for research evidence on a defined topic. The decision to limit searches to 1996 onward had limited effect on overall volume as the number 'lost' when the limit applied was small. Northway and colleagues found only five studies for 1995 (Northway, Mitchell et al., 2006). Our searching employed more extensive terms than Northway and colleagues but we did not undertake extensive citation searching or hand searching of key journals as they did (Northway, Mitchell et al., 2006).

We limited our searches using strategies designed to identify research studies. This strategy was designed to increase the specificity of our searches. Although the published evidence on the HIRU filters used suggests that their sensitivity is high, they may not perform so well in a field where so much research is descriptive and poorly indexed (Cullum, 1997). However, it is likely that these searches work best for clinically relevant studies (HIRU, no date) and so while we may have missed further research of a background or descriptive nature, we are likely to have identified most studies which would provide direct evidence to guide practice in the sense generally recognised by the evidence-based practice movement. Experience from other areas suggests that it is unlikely that there is a large body of high quality 'gray' literature although a search for unpublished research in PhD and other theses may yield quality unpublished research, albeit in a format that renders it inaccessible to practitioners. Fundamentally our conclusion as to the overall volume of evidence is the same as Northway's – it is highly limited.

Conclusions & Recommendations

It is unclear if the trend of increasing volume noted in the first part of the period covered in this review is continuing but overall activity remains low with a peak of 25 research publications noted in one year. Thus any deficit is unlikely to be remedied in the near future at current rates of production of evidence. In addition to low volume, the scale and quality of the research base is also limited. The fundamental conclusion that must be drawn from this review is that relatively little '*learning disability nursing research*' exists in so far as that is represented by published accounts of research in reviewed journals. There is a particular lack of applied clinical research to support learning disability nursing practice.

Although hard to assess, the volume of activity seems to be disproportionately low given the level of need and judging from the size of the specialism in the UK. Funded studies appear to be particularly limited in number and at a lower level to nursing research as a whole. The overall quality of the research reviewed was poor in terms of strength of designs used and sample sizes. Therefore, based on this, we must judge that the current body of learning disability research is not fully fit for purpose in terms of its extent, quality or quantity if a significant part of the purpose is to develop and evaluate interventions for practice and in practice.

The UK makes a disproportionately *large* contribution to the international literature and it seems likely that it is the existence of a distinct specialty that contributes to this. However, this distinctive feature generates a particular problem in a critical mass of research activity, already small, cannot be supported by obvious international links. Northway et al further noted the lack of cross citation to UK research in international studies.

The needs which learning disability nursing address are significant and the role of specialist nurses in meeting them is established within the UK at least. It is beyond the remit of this review to comment on whether specialist nurses are *necessary* to meet the needs but it is worth observing that the neglect of this client group in international research is on a far greater scale than in the UK. However, if the work of learning disability nursing is to be properly supported by research we recommend the following.

- There should be a clearer priority on research aimed at determining the impact of interventions and services delivered by nurses in terms of effectiveness and the experiences of clients and carers
- In the absence of a formal needs analysis, obvious areas to prioritise are mechanisms for improving access and experience of general health care and interventions for behavioural problems (or to support parents in this regard)
- Given the limited resources available there should be a reduction in activity aimed at simply describing life experiences in general as although this is itself valuable other practice disciplines, social science in general also operate within this area
- Research should be more programmatic. Individual researchers should pay close attention to recommendations of previous research and recognise the value of replication
- Given the limited resources available and the demands that research places on participants, more attention should be given to quality in the design of studies
- Strategic alliances should be formed with cognate disciplines. This may be with the wider nursing research community or with other disciplines such as psychology or social work.
- Researchers should seek out international contacts to foster further opportunities for cross fertilisation and identify potential opportunities for international collaboration. The small but significant level of activity within Europe suggests that local alliances with nurses working within socialised health systems may be possible
- Current and potential research leaders – academics, nurse consultants and others – should be identified and present capacity assessed in order to identify supportive actions to increase capacity.

- Consideration should be given to strategic investments which could be used to generate critical mass. Potential options might be focussed research funding or research centres
- Consideration should be given to *how* much of the small scale descriptive research is generated. Since much of this may emanate from student research, responsibility must rest on academic supervisors in providing guidance on topic selection.

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Appendix – search limits used (OVID)

limit to ("diagnosis (sensitivity)" or "diagnosis (specificity)" or "diagnosis (optimized)" or "prognosis (sensitivity)" or "prognosis (specificity)" or "prognosis (optimized)" or "reviews (1 term high sensitivity)" or "reviews (1 term high specificity)" or "reviews (1 term min difference)" or "reviews (2 or more terms high sensitivity)" or "reviews (2 or more terms high specificity)" or "reviews (2 or more terms min difference)" or "qualitative studies (1 term high sensitivity)" or "qualitative studies (1 term high specificity)" or "qualitative studies (1 term min difference)" or "qualitative studies (2 or more terms high sensitivity)" or "qualitative studies (2 or more terms high specificity)" or "qualitative studies (2 or more terms min difference)" or "causation-etiology (sensitivity)" or "causation-etiology (specificity)" or "causation-etiology (optimized)" or "economics (1 term high sensitivity)" or "economics (1 term high specificity)" or "economics (1 term min difference)" or "economics (2 or more terms high sensitivity)" or "economics (2 or more terms high specificity)" or "economics (2 or more terms min difference)" or "treatment (1 term high sensitivity)" or "treatment (1 term high specificity)" or "treatment (1 term min difference)" or "treatment (2 or more terms high sensitivity)" or "treatment (2 or more terms high specificity)" or "treatment (2 or more terms min difference)")

limit to ("0200 clinical case study" or "0400 empirical study" or "0410 experimental replication" or "0430 followup study" or "0450 longitudinal study" or "0451 prospective study" or "0452 retrospective study" or "0600 field study" or "0800 literature review" or 1200 meta analysis or 1600 qualitative study or 1800 quantitative study or "2000 treatment outcome/randomized clinical trial")

limit to (clinical trial or clinical trial, phase i or clinical trial, phase ii or clinical trial, phase iii or clinical trial, phase iv or controlled clinical trial or evaluation studies or meta analysis or multicenter study or proceeding or proceedings or protocol or "questionnaire/scale" or randomized controlled trial or research or research instrument or "review" or short survey or "systematic review" or validation studies)limit 22 to 1

limit to (peer reviewed journals or blind peer reviewed journals or double blind peer reviewed journals or editorial board reviewed journals)