The Journal of DementiaCare Research Review

This section aims to provide a channel of two-way communication between researchers and practitioners in the expanding field of social, psychological and nursing research in dementia care, including all aspects of nursing and care practice, communication and the environment.

People with a learning disability and dementia: reducing marginalisation

While the voice of people with a learning disability and people with dementia are increasingly included in research and practice, the same cannot be said for people who have both a learning disability and a dementia. **Karen Watchman** reviews the literature in order to identify factors that have contributed to this lack of consideration in health and social care policy and practice.

Abstract: The awareness that people with a learning disability, particularly Down's syndrome, are at risk of dementia at a younger age brings an associated need for clarity over service planning and delivery. In order to record changes and developments in approaches, research literature documents the changing history of people with a learning disability and, separately, people with dementia. We do not have the same knowledge about the most appropriate ways of supporting individuals who have both a learning disability and a dementia. People will already experience social exclusion due to society's interpretation of their learning disability and this review identifies from the literature factors that have contributed to the further marginalisation of this group. The review highlights the need for accurate data and statistics, an individualised approach to sharing information about the diagnosis, general and specialist training, an increased use of adapting methods of communication as dementia progresses and a consistent staff approach across care settings.

Keywords: Learning disability, Down's syndrome, dementia, marginalisation, literature review.

This article has been developed from a literature review undertaken as part of PhD research at the University of Edinburgh: *At a crossroads in care: the increased marginalisation of people with Down's syndrome and dementia*. The aims of the PhD were to build understanding of experiences after a diagnosis of dementia, and to foreground research methods that enable the inclusion of people with a learning disability and dementia in research. In the process, factors influencing the further marginalisation of this already socially excluded group were identified in the study.

The growing awareness that people with a learning disability, especially Down's syndrome, are at risk of dementia at a younger age brings an associated need for clarity over service planning and delivery. Research literature documents the changing history of people with a learning disability and, separately, that of people with dementia. This includes knowledge of where people are cared for, approaches to providing support and moves towards greater inclusion in practice, policy and research. We do not have the same evidence base about the most appropriate ways of supporting individuals who have both a learning disability and dementia.

The literature review showed how, over time, both learning disability and dementia services have made attempts to break away from their troubled past in terms of exclusion and segregation, towards greater inclusion, empowerment and self advocacy for many. At the same time, services for people with both a learning disability and dementia have struggled to find a sense of identity, often caught between both services.

In order to contextualise learning disability and dementia, a summary of this historical overview is presented, followed by a discussion of key issues identified in the literature. This considers possible reasons for the lack of an

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This Research Review section of *JDC* is now fully peer reviewed. It aims to keep readers up to date with the fast expanding field of social, psychological and nursing research in dementia care. By this we mean every aspect of person-to-person communication, nursing and care practice and organisation, and the influence of all aspects of the environment. The aim is to provide a channel of two-way communication between researchers and practitioners, to ensure that research findings influence practice and that practitioners' concerns are fed into the research agenda. Each Research Review will include a comprehensive review of significant research in a subject area. See guidance on p39; please contact Sue Benson sue@hawkerpublications.com if you would like to contribute a review.

We also welcome the following:

- short reports of research projects – see guidance on p39 and on our website;
- notice of the publication (recent or imminent) of peer reviewed papers with practical relevance to dementia care, and/or short comment on important papers;
- research reports available for interested readers;
- requests or offers for sharing information and experience in particular fields of interest.

evidence base in this area and the potential for the increased marginalisation of people with a learning disability and dementia. These issues are:
- the lack of statistics and subsequent future planning
- the lack of consistency when sharing the diagnosis of dementia
- the debate over general versus specialist support
- the lack of accommodation pathway options across care settings.

Search strategy

The search terms used for the literature review included both UK and international terminology. This meant that learning disability, intellectual disability, Down and Down's syndrome were used in addition to dementia and Alzheimer's disease. Six databases were searched (Psychoinfo, Web of Knowledge, CINAHL, Medline, EMBASE and Sociological Abstracts). In order to gain a historical overview of each group, no date restrictions were used. Position papers, grey literature, conference reports and editorials were included.

Historical overview

The emerging link between learning disability and dementia was recorded in medical journals in the 1970s (Burger & Vogel 1973). Clinical studies reported in the 1980s offered more conclusive evidence (Heston *et al* 1981; Glenner & Wong 1984). Initial research in this field was predominantly written for medical and scientific audiences, because the evidence came from identifying pathological changes at post mortem (Yates *et al* 1983; Mann *et al* 1985). During the 1980s, 1990s and into the 2000s life expectancy was gradually increasing and this led to the wider awareness of the impact of associated health conditions such as dementia.

This change in life expectancy coincided with the movement towards independent living for people with a learning disability. It was also at this time that Kitwood (1997) was writing about the importance of person-centred care for people with dementia. Despite this, neither independent living, nor person-centred approaches, were evident in research or literature for people with a learning disability and dementia.

During the period when normalisation (Wolfensberger 1982) was gaining prominence in the field, social research into people with a learning disability and dementia began to emerge. The normalisation movement introduced a set of principles that stressed the importance of people with a learning disability living an ordinary life, doing ordinary things with ordinary people, essentially having a 'normal' life. This raised the profile of people with an intellectual disability by emphasising the need to be among others and valued for themselves. More recently it has been observed (Chappell *et al* 2001) that normalisation was about the views of others, rather than the views of people with an intellectual disability themselves, and that the movement did not acknowledge this power imbalance. Similarly, studies at this time largely focused on the perspective of the family carer as most people with a learning disability were, by this time in the 1990s, growing up in the family home (Prasher & Filer 1995). Research focused on the age of people at onset, the rate of progression and the difficulties that became evident when dementia was diagnosed. These difficulties included changes in behaviour (Prasher & Filer 1995), changes in speech (Cooper and Prasher, 1998) and changes in physical condition with increased likelihood of, for example, epilepsy in the later stages (Palop 2009).

> The importance of sharing the diagnosis, and discussing the changes being experienced, is not recognised for people with a learning disability

It would seem logical that person centred approaches and strategies, as developed for people with a learning disability and people with dementia generally, should lead to the same approaches being evident in the support of people with both a learning disability and dementia. In reality, much of the literature falls short of drawing together these approaches. Instead, the lack of an evidence base contributes to a lack of knowledge in practice, with formal and family carers often unclear of support options available.

Lack of accurate statistics

To a large extent, the interventions that take place with people who have a learning disability and dementia are reactive, rather than proactive. People with a learning disability, as a group, are not specifically identified in policies that relate to either learning disability or dementia, although some organisations have developed local or professional guidelines (British Psychological Society, 2009). As a result, it has been open to interpretation how far guidance for supporting for people with a learning disability and people with dementia are applicable, and appropriate, for those with both a learning disability and dementia. Part of this difficulty comes from the lack of projected or actual statistics, both at a local and national level, on the numbers of people in the UK who have a learning disability and dementia.

There is little acknowledgement in policy that not everyone with dementia is an older person, nor that before a diagnosis of dementia an individual may already be living with reduced cognitive abilities and different communication strategies. As a result, there is the potential for people with a learning disability and dementia to be considered as different from others with a learning disability or people with dementia, thus extending their exclusion.

Disclosing the diagnosis?

Sharing the diagnosis, or discussing the changes being experienced post-diagnosis, as recommended in the general population (Bakker *et al* 2010) allows the person to have more gradual realisation of the impact and potential implications of the diagnosis. Alongside ongoing support and information this would see giving the diagnosis not as a 'one point in time' occurrence, but as an ongoing process (Vernooij-Dassen *et al* 2006, p298). The importance of this is not recognised for people with a learning disability and dementia. The development of a framework or practice guidelines for giving a diagnosis of dementia to a person with a learning disability and dementia has not been addressed, although work on sharing the diagnosis has progressed with other health conditions such as cancer (Tuffrey-Wijne & Hollins 2009). It is impossible to find out about individual experiences of dementia if the person is not aware of their diagnosis. Reasons for the diagnosis not being shared in the general population include the decision by others not to attach a label to the person, who may also already experience stigma by nature of age (Widrick & Raskin 2010). Research suggests that people in the general population would want to know of any future diagnosis (Jha *et al* 2001), but this question has not been asked of people with a learning disability.

The dementia strategies in England

(Department of Health, 2009), Scotland (Scottish Government, 2010) and Northern Ireland (Department of Health, Social Services and Public Safety, 2011) acknowledged the importance of the diagnosis being shared in order to maximise post-diagnostic support. Although recognition of the increased incidence of dementia in people with a learning disability was included in all strategies, none was specific about subsequent interventions or support for those who also had a learning disability.

General versus specialist care

The international debate around general or specialised care for people with a learning disability and dementia began in the 1990s with the work of Janicki and Dalton (1999), which coincided with the increase in awareness and knowledge of the link between the two conditions. Janicki and Dalton considered whether services should be located and accessed within the general ageing system, within the general learning disability system or a more specialised combination of the two. This debate is evident when considering accommodation, suggesting a lack of clarity over where people with a learning disability and dementia call 'home'.

Many people with a learning disability will have a pre-existing network of support, as they have always relied on others for care and support. As a result, a different process is generally observed after a diagnosis of dementia, for example for many family carers this is a continuation of their previous role. A model of care seen in literature, that considers accommodation options (Janicki and Dalton, 1999), recognises the lack of a clear or recommended pathway. As the debate continues over an appropriate location of care, the approaches of 'referral out', 'ageing in place' and 'in-place progression' remain relevant. These are considered below in relation to more recent research.

Referral out

Referral out involves a move for the person with a learning disability to a generic social care environment or, if health needs are prominent, to a nurse led facility such as a nursing home. Since this model was developed, questions have increasingly been asked in the UK as to the suitability of relocation to care or nursing homes (Michael and Richardson, 2009). This is partly due to the differences in age of the resident, for example a person with Down's syndrome may be in their forties or fifties when dementia is diagnosed. A further factor is the pre-existing difference in communication, in addition to changes required as people become increasingly non-verbal. Thompson and Wright (2001) noted the frequent inappropriate placement and referral out of people with intellectual disabilities to generic older people's services. Despite having this awareness, literature does not provide accurate figures of dementia in people with Down's syndrome in care homes for older people. The lack of statistics means this group is not recognised as a key social policy issue thus leaving these people 'hidden' within the care system.

> Literature does not provide accurate figures of dementia in people with Down's syndrome living in care homes for older people

A lack of staff training and inadequate knowledge of learning disability in people with dementia leads to needs not being addressed in a generic care home (Hoe et al 2009). This option is often the one most readily available due to shorter waiting lists and higher turnover of residents. It also occurs in response to a crisis situation in the family home, should the carer become incapacitated or if, after a stay in hospital, a move home is no longer appropriate (McCarron et al., 2005). In such circumstances the extent of choice offered to people with a learning disability over the change in accommodation remains unrecorded.

Ageing in place

Janicki and Dalton (1999) referred to a person with a learning disability and dementia remaining in their own home environment, with adaptations, after a diagnosis of dementia as 'ageing in place'. This includes incorporating staff training in dementia into service provision, and environmental adaptations, to minimise the effects of dementia on the person and others living in the same environment.

Many people age in place in learning disability group homes. This is likely to be somewhere they have lived for many years. Despite this being the place where they may be known best, it has been shown to result in areas of difficulty after a diagnosis of dementia. For example, concern was raised by other residents with a learning disability in group homes that the person with dementia was seen as having 'special privileges' if they were treated differently by staff (Forbat and Wilkinson, 2008, p.7). Resentment was apparent if changes, or environmental adaptations, which are recommended in dementia care, were made to their shared home. The resident who had dementia showed little or no awareness of having dementia or what this implied; conversely the impact was strong on their peers in the group home (Wilkinson *et al*, 2004).

Ageing in place can also happen in the family home. In twenty-first century Scotland the majority of people with a learning disability live with family, either a parent or sibling (Scottish Executive, 2000). Family carers have usually been the primary carer for the lifetime of the person they care for which may be for thirty, forty or even fifty years. One third of all people with a learning disability in the UK living at home are cared for by a relative who is aged over seventy (Department of Health, 2001). Research regularly highlights the lack of practical support for family carers of people with learning disabilities (Gilbert et al., 2004). Family carers, both parents and siblings, frequently report isolation and lack of knowledge of dementia at all stages, from diagnosis to end of life (Watchman, 2004). Nonetheless, ageing in place, regardless of where that place may be or the support available, is generally seen in literature and policy as the preferred option provided that appropriate ongoing support is available (Bigby, 2008; Scottish Government, 2010).

In-place progression

The third option in Janicki and Dalton's model for people with a learning disability and dementia is 'in-place progression' (Janicki and Dalton, 1999). This refers to a move to, or creation of, a dementia specific environment for people with an intellectual disability. Those with broadly similar levels of need are provided with a range of accommodation options and support in a specialised setting. It allows for progression through stages of dementia whilst the person stays within the same service. Llewellyn (2011) wrote that prioritising the lead service was crucial in meeting the needs of people with an intellectual disability and dementia. She noted a consensus in research that it should be learning disability, rather than dementia care in services for older people who take the lead in provision of support for people with a learning disability and dementia.

Ironically, in-place progression is the option least often seen in the UK. Yet, it

may offer the choice of developing existing learning disability services to create specific learning disability and dementia provision. Absence may be due to care providers not being equipped or financed to adapt premises in order to accommodate people with a learning disability and dementia. There is currently no evidence to show that staff are sufficiently trained, confident or experienced in working solely with this client group. Many have skills in working with people who have dementia, whilst others are competent in their role with people with a learning disability. When enough professionals are currently trained in both, with general and specialist knowledge, this may make in-place progression a more viable option.

Summary

Despite knowing of the link between learning disability and dementia for decades, there is little in research literature to suggest that attempts have been made to bring together knowledge from both services that will inform the culture and ethos of organisations supporting people with a learning disability and dementia. If people are not told of their diagnosis of dementia, or given an explanation for the changes they are experiencing, this restricts their opportunity to take part in decisions that affect their future support or health care needs. Person centred approaches have been developed for people with a learning disability and, separately, for people with dementia. However, there is a lack of clarity in the literature over the most appropriate approach to take with people who have both, just as there is a lack of clarity over the most appropriate accommodation setting or model of care.

The extended life expectancy of people with a learning disability has led to knowledge of the greater incidence of dementia at a younger age, especially in people with Down's syndrome. We know of this link but we do not have an accurate figure in the UK or internationally, or projected figures, of how many people with a learning disability have dementia. The voice of people with a learning disability and dementia is not evident in the way that the voice of people with a learning disability or dementia is increasingly becoming heard; self advocacy is not evident.

Geographical exclusion in large out-of-town long-stay hospitals may have gone, but some people remain increasingly segregated and isolated within their own communities. Although steps have been taken in terms of individualised support, people with a learning disability and dementia remain among the most excluded, either through complexity of their disability, lack of verbal communication and a progressive cognitive condition.

A series of deficits have been identified from the literature that are likely to result in a further increase in the marginalisation experienced by people with a learning disability and dementia. These deficits include the lack of a shared diagnosis, lack of staff training and future planning, lack of adapted communication as dementia progresses, lack of accurate statistics of the numbers affected or predicted, lack of clarity over accommodation options and an increase in isolation. The result is a Cinderella service that reflects our limited knowledge of individual experiences and support needs of this group.

Key points for practice

- The care setting will only remain appropriate if the support provided within it meets individual social, emotional needs, in addition to physical. To achieve this, staff at all levels need consistent training in both intellectual disability and dementia.
- In addition, increased consideration should be given by service planners and providers to the creation of specialised staff in this field.
- One named person should take responsibility for explaining the reasons for changes the person with a learning disability is experiencing. This will enable the diagnosis to be shared in a supportive and individualised manner. Other carers and staff should then be consistent in their approach.
- Learning disability services, which are most likely to have contact before dementia is diagnosed, are best placed to coordinate future care after a diagnosis of dementia.
- Ageing in place is only an appropriate long-term option if the support level continues to increase on an individual basis. It may mean that the person is able to remain in their own accommodation, but this should not be assumed.

Gaps in research literature

The following gaps have been identified when considering what we know of the care and support needs of people with Down's syndrome and dementia:

- An understanding of the experiences of people with Down's syndrome and dementia from their own perspective.
- Examples of good practice in sharing the diagnosis of dementia with a person with Down's syndrome.
- Data reflecting the number of people with Down's syndrome who are, or may be, affected by dementia.
- Strategy for the development of a pathway to support the accommodation needs of people with Down syndrome and dementia, their fellow tenants and carers. This maybe a pathway that makes recommendations in favour of a particular care setting or suggestions as to what is not appropriate. Currently neither exists.
- Recommendations for blending key areas of knowledge from the fields of intellectual disability and of dementia, rather than each working in isolation. ■

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Pain and dementia

Useful articles in the Practice Development Section of *International Journal of Older People Nursing (IJOPN):*

McAuliffe L, Brown D, Fetherstonhaugh D (2012) Pain and dementia: an overview of the literature. *IJOPN* 7 219-226.

This paper offers a brief overview of recent international literature on pain and dementia which indicated a high prevalence of both pain and dementia in older adults in residential, community and acute care settings. Factors contributing to under-assessment include dementia-related factors (such as loss of communication ability) and health professional-related factors (such as inappropriate or non-application of a pain assessment tool and lack of knowledge regarding pain mechanisms and/or dementia).

Walls S, White T (2012) Pain and dementia – an application to practice: an example. *IJOPN* 7 227-232.

Building on the preceding literature review, this paper describes how a module of clinical best practice relating to pain and people with dementia was developed and implemented in a range of aged care settings in Australia.

Nay R, Fetherstonhaugh D (2012) What is pain? A phenomenological approach to understanding. *IJOPN* 7 233-239.

Four phenomenological accounts of pain – its experience and its meaning – highlight that pain is emotional, cognitive and physical. By exploring the essence of pain, the paper encourages nurses to reflect on how their understanding of pain and individual responses to pain can impact on how they recognise, assess and manage pain in older people and especially those living with dementia.

Hazel Heath

The impact of a staff non-uniform policy in a private community long-term mental health care home for older people

By Chris Tattersall and Sally Phillips

Context and rationale

There are strong arguments for the use of uniforms in all areas of health care. These include assisting patients to identify staff, allowing the wearer to feel professional and be perceived as professional and establishing a safe and secure environment. Critics argue that the symbolism associated with uniforms can have a negative effect by reinforcing the 'sick role'.

Methods

A non-uniform policy was introduced into the home.

1. Quantitative data measurement: Six months before and six months after the introduction, data on nineteen residents were analysed, including:

- the prescription of antipsychotic, antidepressant, hypnotic and anxiolytic (anti-anxiety) medications
- the use of prn (as required) medication
- infection rates
- accident reports
- resident participation in planned activities.

Staff sickness rates were also measured.

2. Questionnaires: 14 staff, 7 visitors and 7 resident advocates completed questionnaires describing their preferences for staff wearing uniform or their own clothes and any positive or negative effects of staff not wearing uniform.

Key findings

- No significant statistical results in prescribed medications; accident reports; infection rates or staff sickness.
- No detrimental effect on the rate of antibiotic use when staff wear their own clothes, suggesting no increase in cross-infection rates.
- A positive significant correlation between time since the introduction of the non-uniform policy and an increase in resident participation in activities.
- Questionnaire responses suggested that staff wearing their own clothes made the home feel 'more relaxed'.

What this study adds

Although the sample was small, the residents' increased uptake of activity following the introduction of a staff non-uniform policy is important in the context of literature suggesting that activity should be considered a preventative measure in dementia care. A 'relaxed' atmosphere is associated in previous studies with improved wellbeing, reduced agitation and enhanced social interaction.

Further information

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Keeping people at home

Research presented at Alzheimer's Association's International Conference in July shows that a coordinated, multidisciplinary approach to care in a person's own home can improve quality of life and greatly reduce the need for people with dementia to leave their homes, its authors say. Over 18 months, a team of allied health professionals specifically trained in dementia care conducted a controlled trial involving 303 people with cognitive disorders. Through the use of interventions such as multidimensional needs assessments, memory disorder education and counselling, the team saw a significant drop in the need for participants to be transferred to a care home. Participants also reported improvements in quality of life.

Samus QM *et al* (2012) Efficacy of a multidimensional home-based care coordination intervention for elders with memory disorders: the Maximizing Independence at Home (MIND at Home) Trial. (Funder: Jewish Community Federation of Baltimore).

Drama to aid reflection

The aim of this study was to explore the use of drama as a tool to support reflection among staff working in residential care of people with dementia. It found that drama did seem to help staff see things from the residents' perspective, but that several adjustments are needed both in content of the sessions and methodology of the research. When designing a larger intervention study, sessions should be combined with staff support to make changes in care practice resulting from their increased awareness, the authors say (and to achieve this, the management needs to be stable, committed and supportive).

Bolmsjö I, Edberg AK, Lilja Andersson P (2012) The use of drama to support reflection and understanding of the residents' situation in dementia care: a pilot study. *International Journal of Older People Nursing* doi:10.1111/j.1748-3743.2012.00333.x

Value of case conferences

A case conference is often recommended as an effective instrument for health care professionals to improve the quality of care of a person with dementia whose behaviour is challenging staff. However, a review of research on case conferences found little evidence for their positive effects. This highlights the need for methodologically well-designed intervention studies to provide conclusive evidence of the effects of case conferences, the authors say.

Reuther S, Dichter MN, Buscher I, Vollmar HC, Holle D, Bartholomeyczik S, Halek M (2012) Case conferences as interventions dealing with the challenging behavior of people with dementia in nursing homes: a systematic review. *International Psychogeriatrics* Aug 10: 1-13. [Epub ahead of print]. http://www.ncbi.nlm.nih.gov/pubmed/22883019

BPSD training evaluated

This review evaluated the effectiveness of staff training interventions for reducing 'behavioural and psychological symptoms of dementia' (BPSD). A systematic literature search identified 273 studies. Twenty studies, published between 1998 and 2010, were found to meet the inclusion criteria. Overall, there was some evidence that staff training interventions can impact on BPSD: twelve studies resulted in significant symptom reductions, four studies found positive trends and four studies found no impact on symptoms. No links were found between the theoretical orientation of training programmes and their effectiveness. Training was also found to impact on the way staff behaved towards residents. However there were numerous methodological weaknesses and many studies did not adhere to recommended guidelines for the conduct of trials. There is an urgent need for more high quality research and evidence-based practice in BPSD, the authors say.

Spector A, Orrell M, Goyder J (2012) A systematic review of staff training interventions to reduce the behavioural and psychological symptoms of dementia. *Ageing Research Reviews* Jul 20 [Epub ahead of print] http://www.ncbi.nlm.nih.gov/pubmed/22820151

Authentic partnerships

People living with dementia are often assumed to lack the capacity to be involved in their own care and the care of others. Drawing on their experience in practice and research, the authors present an alternative approach that views persons with dementia as equal partners in the context of dementia care, support and formal services

Dupuis SL, Gillies J, Carson J, Whyte C (2012) Moving beyond patient and client aproaches: Mobilizing 'authentic partnerships' in dementia care, support and services. *Dementia* 11(4) 427-452.

Research Review

This research section of *JDC* is now fully peer reviewed. We invite the following contributions from researchers:

1. Research review articles

A review of research and evidence on a specific topic will be included in each issue; this may be based on a literature review already undertaken. Please contact Sue Benson (sue@hawkerpublications.com) to agree on the title and scope of your proposed review (in case we have a similar article in the pipeline already). Review articles should be around 3000–4000 words in length (without references) and should:

- acknowledge the nature and scope of published research and evidence on the topic
- briefly state the search strategy in terms of databases, search terms, inclusion criteria and the technique used to review the research
- set out the major studies under headings or themes
- offer a critique and evaluation of the research and how it was conducted
- highlight the implications for people with dementia and carers
- draw conclusion on the relevance of the findings to services, professionals and staff supporting people with dementia.
- identify any implications for future research.

References should use the Harvard format shown throughout *JDC*.

Full weblinks should be given for online sources cited.

2. Short reports

Short reports summarising a study or practice/service evaluation should be 400-500 words in length and use the following headings.

- Title of the study
- The context and rationale for the research
- What is already known about the subject
- How the study was conducted
- Key findings
- What this study adds to existing knowledge
- How or where readers can find further information, a reference or weblink.

An example of a Short Report is *The impact of a staff non-uniform policy in a private community long-term mental health care home for older people*, on p38

We also welcome (send to sue@hawkerpublications.com):

- Notice of the publication (recent or imminent) of peer reviewed papers with practical relevance to dementia care
- Short comment on important research papers recently published, drawing practitioners' attention to new evidence and key points that should inform practice
- Research reports that are available for interested readers
- Requests or offers for sharing information and experience in particular fields of interest.