

Home for Good?

**Preparing to support people with learning difficulties
in residential settings when they develop dementia**

Heather Wilkinson, Diana Kerr, Colm Cunningham and Catherine Rae

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RESEARCH *INTO* PRACTICE



Pavilion



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Executive summary

As increasing numbers of people with learning difficulties live to an older age, they encounter age-related illnesses and conditions such as dementia. These demographic changes create pressure on the planners and providers of learning difficulty services. Yet despite these trends, there is still a lack of useful information and evidence on how best to provide services that are needs-led, multidisciplinary and supportive (Watchman, 2003).

Models of care

For a person with learning difficulties and dementia, there are a number of potential pathways along a continuum of provision that they might follow after diagnosis. These include:

1. 'ageing in place', where they remain in their own accommodation with appropriate supports adapted and provided
2. 'in place progression', where staff and the environment are continually developed and adapted to become increasingly specialised to provide long-term care for the person with dementia within the residential service (but not necessarily their own accommodation)
3. 'referral out', where the person will be moved to a long-term nursing facility or other type of provision.

(Janicki & Dalton, 1999a; Janicki *et al*, 2000).

Findings

Diagnosis as a starting point

The availability, timing and management of a diagnosis all have a significant influence on the experience of the individual with dementia and the model of care they receive.

Pathways of care

Even where a formal diagnosis had been given, there was often a lack of any formalised route for the management of the individual's care, or any consistent, coherent, systematic or relevant training given to staff.

Experiences of co-residents¹

When someone develops dementia in a care home setting, it can have a potentially negative effect on the other people living there. Most residents, although concerned, seemed to accept that the person was 'ill' and therefore couldn't help some of the things that they were doing. Co-residents' understanding varied, depending on the extent to which they had been given information to enable them to understand that the condition was not in the control of the person with dementia.

The experiences of relatives

Most of the people in the survey had little or no contact with relatives. The five relatives interviewed expressed general anxiety that

¹ People who live with the person with dementia

their relative might have to be moved, gratitude to staff, lack of awareness and knowledge about dementia and a desire for more information.

The experiences, knowledge and working practices of staff

The experiences and expectations of staff may be a key determinant of the chosen care pathway or model. The majority of the staff expressed an experience of floundering and having to react to changing needs. Few staff had previous training in supporting people with dementia.

The high levels of staff commitment resulted in a high level of emotional labour and sense of personal responsibility, doing extra shifts or working as waking night staff when only officially employed as sleeping cover. Staff would cope rather than ask for help which might, they feared, result in the person being moved.

Key issues that impacted on staff and residents' experiences

Night-time issues and coping strategies

The presence of waking night staff was a critical factor in supporting the person to remain at home. The provision positively affected both the experience of the person with dementia and the other residents.

Eating and drinking

Eating and drinking figured prominently as areas of concern, tension and conflict. Staff need to be aware of the many obstacles to eating well and, more importantly, they need to know how to access advice on ways to overcome the difficulties.

Staff perspectives on training

There was a dramatic difference between the sites visited in terms of quality of training, if training had been given at all. Yet in all the sites, staff consistently raised the need for ongoing and appropriate high-quality training.

It is important for staff to be trained *before* anyone develops dementia within their service, so that the service is 'dementia-ready'.

Environmental issues and issues in relation to pain

Two areas emerged as significant, through the general *lack* of attention paid to them. These were environmental adaptation and pain management, both of which are critical to the care and support of people with dementia.

Strategies for providing services when someone has to move

In a number of instances, the changing needs of the person with dementia led to him or her being moved, either temporarily to a hospital, or permanently to hospital or a nursing/care home for older people. Decisions about when to move were often dictated by a crisis.

Decisions about where to move were often based on available resources, rather than on a coherent strategy. With only one exception, these moves were seen as detrimental to the health and well being of the person.

Models of service delivery

The models of service delivery across the six study sites operated as follows.

Option A: Ageing in place

All of the places visited were endeavouring to maintain people in their original setting. Only one site in the study had supported a person with learning difficulties through their dementia, to death.

Option B: In place progression

No completed examples of 'in place progression' were observed. In one site, however, a decision had been made to develop an 'in place progression' option with a house providing specialist dementia care built in the grounds of the present accommodation, connected to it by a corridor. (At the time of going to press, this proposal had not secured funding.)

Option C: Referral out

This option was one that most sites had experienced and, with one exception, was seen as a negative experience for the person with dementia.

Outreach as a model

This did not exist in any of the sites. This model would use resources external to the residential service and would provide additional support to maintain the person in their own home. An outreach model could

be delivered through a coordinated service provided by designated staff in the locality, for example, within a social work centre or a community learning difficulties team. This provision could incorporate the following elements:

- extra support staff for the residents without dementia; this would release staff in the home to give time to the person with dementia who they know, and who knows them
- the use of palliative care services
- the use of other professional expertise, such as speech and language therapy
- the availability of staff to give general advice and support on dementia
- the provision of good-quality, specific dementia respite care.

Conclusion

The data from this study suggest that there is not one clearly defined response currently operating in the UK. The options illustrated above are not without their problems and dilemmas. Responses are often determined by resources rather than need. The complexity of the needs and demands associated with supporting people with learning difficulties and dementia in care home settings means that, at the moment, all three options within this model and a combination of aspects of this model will continue to be used.

Chapter One

Introducing models of care for people with learning difficulties and dementia

One of the most pressing issues facing UK service providers in the field of learning difficulties is how best to provide support and care to an ageing population across a variety of settings. The majority of adults with learning difficulties live at home, often with elderly parents (Moss & Patel, 1992). Statistics suggest that 63% of adults with learning difficulties live in private households, usually with their own family (Department of Health, 2001a) and that most support is provided by parents, brothers and sisters and other relatives (Scottish Executive Health Department, 2000). For adults not living in their family home, the dominant form of residential services for people with learning difficulties is small-scale, community-based, staffed housing (Perry *et al*, 2000). It is individuals in this type of housing who are the focus of this study.

As increasing numbers of people with learning difficulties live to an older age, they encounter associated illnesses and conditions such as dementia. These demographic changes create pressure on the planners and providers of learning difficulties services. Despite these clear trends, there is still a lack of useful information and evidence on how best to provide services that are needs-led, multi-disciplinary and supportive (Watchman, 2003).

Deinstitutionalisation since the 1960s has resulted in changes in the models of care

provision, underpinned by the promotion of individual choice and quality of life through supporting individuals to live in the community (Wolfensberger, 1972). However, the demographic changes that have resulted in an ageing population create specific challenges to these values and approaches. The prevailing ageist attitudes towards older people in the general population may well be replicated in attitudes to older people with a learning difficulty.

Often, decisions made around health and social care provision for older people with learning difficulties who develop dementia are based on a common assumption that it is best to support individuals to remain in their own homes for as long as possible. At present, there is little understanding or evidence of how this can be best achieved, especially when the individual experiences the effects of increasing cognitive impairment from dementia. With the onset of dementia, carers (either family or paid) can find it increasingly problematic to support the person in the community (Mittleman *et al*, 1996). If people with learning difficulties who develop dementia are to be supported in their own homes, then administrative, financial and philosophical/practice elements of community care policy need to be redefined urgently at all levels (Janicki & Dalton 1999b; Watchman, 2003).

Overview of epidemiological patterns

Advances in medical and social care for people with learning difficulties have led to an increased life expectancy² (Alzheimer's Society, 2000; Baird & Sadovnik, 1987; Holland *et al*, 1998; Janicki, *et al* 1999). For a person with Down's syndrome, life expectancy has increased dramatically from an average of only nine years in the early 1900s to an average of forty-five years in the 1990s (Baird & Sadovnik, 1987). (See Carr (2003) for a review of patterns of ageing for younger people with Down's syndrome.)

Producing exact information on the numbers of people in the population with learning difficulties is difficult, especially for individuals aged forty and over. Recent reviews in the UK give some indication of demographics, with estimates of about 210,000 individuals with severe and profound learning difficulties in England, 25,000 of whom are over the age of sixty (Department of Health, 2001a) and estimates of around 12,000 people with learning difficulties in Scotland (Scottish Executive Health Department, 2000). In predicting forthcoming trends it is expected that the number of people with learning difficulties will continue to grow by over 1% a year over the next 10 years (Scottish Executive Health Department, 2000; Department of Health, 2001a).

Reports differ on the numbers of people with learning difficulties who develop dementia. A British study predicted that 22% of older people with learning difficulties may be affected by dementia, with figures of 16% for people aged sixty-five to seventy-four, 24% for people aged seventy-five to eighty-four and 70% for people aged eighty-six to ninety-four (Cooper, 1997a). A more recent American study indicated a prevalence of dementia of

3% for people aged forty and older, 6% for people aged sixty and older and 12% for people aged eighty and older (Janicki *et al*, 1999, 2000).

Studies specific to a population of people with Down's syndrome on the prevalence and presentation of dementia showed an increase of 3.4% in the thirty to thirty-nine age group, 10.3% in the forty to forty-nine age group and 40% in the fifty to fifty-nine age group (Holland *et al*, 1998). For people with Down's syndrome, estimates of incidence tend to vary from an incidence of 75% for individuals aged sixty and over (Lai & Williams, 1989) to 54.9% for people aged between sixty and sixty-nine (Prasher, 1995), and down to only 36% for the fifty to fifty-nine age group (Thompson & Wright, 2001).

Overview of models of care

Models of care in the learning difficulty field have developed through three key phases (Bradley & Knoll, 1990), from institutionalisation and segregated care, through a process of deinstitutionalisation and community development, to the current aim of community membership (Heller, 1999). By the 1990s, models of provision specifically for older people with learning difficulties were conceptualised. Such provision ranged across a continuum from the most segregated specialist provision specifically for older people, through services for older people with learning difficulties as part of the general services for older people, and more individualised routes based on use of any mainstream or specialist services (Ward, 1998; Heller, 1999).

One way of looking at how this continuum relates to people with learning difficulties and dementia is to focus on the potential

² It is important to note that trends differ between people with Down's syndrome and people with an unspecified learning difficulty. These differences are not always made explicit but, where the differences are noted separately, they are reported as such in this review.

pathways the person might follow after a diagnosis of dementia:

1. 'ageing in place', where they remain in their own accommodation with appropriate supports adapted and provided
2. 'in place progression', where staff and the environment are continually developed and adapted to become increasingly specialised to provide long-term care for the person with dementia within the residential service (but not necessarily their own accommodation)
3. 'referral out', where they will be moved to a long-term nursing facility or other type of provision.

(Janicki & Dalton, 1999a; Janicki *et al*, 2000)

A high level of financial, organisational and staffing commitment is required to support an individual to successfully 'age in place', especially as medical and nursing needs increase (McCarron *et al*, 2002). Commitment is also required to support 'in-place' progression and staff training and retention, and the physical design features of the building are fundamental to this route.

In homes where more than one resident develops dementia, the resulting combination of severity of care demands created by one resident with dementia and the massed demand created by several residents with dementia can lead to a 'tipping effect' (Janicki *et al*, 2000). Where the demands become too much, a resident may be moved on. The effect on the atmosphere within a house, and the stresses on staff and other residents, require constant re-evaluation and decisions around staff workloads and costs of care. Even where only one resident has dementia, the care demands can 'shift so notably that staff can no longer provide the expected level of care' (Janicki *et al*, 2000, p398) and the person will be moved.

At present, regardless of their current living situation, people who have learning difficulties are often moved out of their homes and into nursing care when their needs increase (Thomson & Wright, 2001). Such a move is generally considered unsatisfactory (Moss, 1992; Thompson & Wright, 2001). In comparison to homes designed specifically for adults with learning difficulties, these general settings tend to provide a poorer level of support, especially in terms of individualised programmes and community involvement (Moss, 1992).

Staffing issues

Providing adequate care for someone with dementia is heavily reliant on adequate staffing and the importance of clarity in job roles, especially across nursing and social care. There is a need for a mix of paid and unpaid support to provide flexible and comprehensive services, and for the recognition that natural support systems for current cohorts of older persons may have been removed or destroyed in the past, through institutionalisation (Wilkinson & Janicki, 2002).

One of the key issues for staff working in residential settings with individuals with diminishing abilities is the required shift in approach away from a focus on the development and learning of new skills; with the onset of dementia, staff need to work to maintain the person's skills and, indeed, to support them through the loss of skills and abilities. This highlights the 'contradiction between the reality that the disease presents and the ideology that has been the basis for the delivery of care in the field of intellectual disability' (Janicki *et al*, 2000, p392).

In addition, the emotional labour required in supporting someone with dementia is often overlooked, and yet it has been found that the emotional challenge to staff and

residents is profound (Weaverdyck *et al*, 1998). Hurley & Kennedy (1997) noted that the key characteristic in staff caring for someone with dementia was their ability to meet the unique challenges and their commitment to do so.

Kerr (1997) highlights that people with Down's syndrome and Alzheimer's disease have 'the same basic needs as anyone else. They do however, have some specific needs which require a more responsive and tailored approach' (1997, p73). Extra demands can be placed on services because:

'...they are more likely to experience much more rapid changes in the progression of the disease than people in the general population. They need more reviews and assessment of need. They have fewer skills to draw on to help them mitigate the effects of the disease and will often have a more complex set of needs than that of the general population. More demands are made of the people working to support them.' (Kerr 1997, p73)

With limited information on the changing care needs of people with learning difficulties and dementia, it remains difficult to predict future resource requirements and how best to respond to changing needs (McCarron *et al*, 2002). The time and the tasks involved in caring for someone with dementia are significantly different to the time spent with someone with learning difficulties without dementia (McCarron *et al*, 2002). Time and resource requirements also vary depending on the stage of the dementia (McCarron *et al*, 2002). Any model of care has to pay attention to these different and changing needs that require differently trained staff, programming and attention to environmental issues (McCarron *et al*, 2002).

Social policy and economics, often related to staffing rather than individual choice

(Janicki & Dalton, 1999b), usually determine where an adult with learning difficulties lives. Certainly, little is known about the understandings and experiences of people with learning difficulties themselves of dementia. Recent work on choice and opportunities for people with learning difficulties and dementia highlighted the limited understanding of their experiences and the need for further work in this area (Stalker *et al*, 1999).

The imperative for services to take account of the views and experiences of people with learning difficulties who live and work with people with dementia is clear (Wilkinson *et al*, 2003). However, models of provision have not previously taken the views of services users and their experiences of dementia into account. The key perspectives of people with learning difficulties who have lived with, or are living with, someone with dementia, are a key part of this study.

Conclusion

Demographic and service changes are leading to increasing pressure on planners and providers of services for people with learning difficulties, to address how best to provide support and care for someone who develops an age-associated illness such as dementia. By reviewing early attempts at outlining possible models of care, the dilemmas around the best way to support a person are highlighted. Can an individual be supported to 'age in place' at the same time as meeting the needs of family, staff and other residents? As the condition progresses, can the best care be provided through the end-of-life stages? In developing services, the issue is not simply for a person with learning difficulties to age and die in place, but is also how this process can best be supported through the complex staffing, service and resource implications.

Chapter Two

Methods and sample

The study was designed to explore the following three questions.

1. What are the current models of practice for supporting people with learning difficulties and dementia?
2. What are the key issues relating to people with learning difficulties with dementia living in care home settings?
3. Describe some examples of best practice in care home provision for people with learning difficulties and dementia.

The work was carried out over a six-month period between 1 December 2002 and 31 May 2003. 'Care home (residential) setting' was defined as 'a formal service provision with a minimum of four residents'. A case study approach, in combination with semi-structured interviews and focus groups, was employed.

Case studies

The fieldwork involved six case study sites where service providers had recent or current direct experience of supporting people with learning difficulties and dementia.

The six sites visited were a mixture of voluntary, private and statutory providers located across the UK. The age range of the residents who took part in the study across the sites ranged from people in their early thirties to those in their seventies.

In each case study site, data were collected on the following areas:

- the experiences of staff and family involved when the person they care for develops dementia
- the experiences of people with learning difficulties who live with a person(s) who has learning difficulties and dementia
- the practical strategies and tools used to maintain the individual in an appropriate care home setting.

Interviews and focus groups

Across the six locations, one-to-one interviews took place with managers, direct care staff, co-residents where appropriate and family members where available. Focus groups were held with co-residents at two of the sites. The number of interviews was as follows: 10 managers; 22 direct care staff (including night staff); 13 co-residents; and 5 family members, giving a total of 50 interviews. Interviews focused on case studies of 18 residents with a dementia.

Sample and consent

There were three stages in the sampling process:

1. identifying and making contact with sites
2. identifying and getting consent to participate from staff and relatives
3. identifying and getting consent from residents.

Sites were identified through a process of prior knowledge of residents or the service,

The sample of people with learning difficulties and dementia³

Name	Gender	Age/group	Learning difficulty*	Diagnosis confirmed**
Penny	F	50s	LD/DS	Y
Tommy	M	50s	LD/DS	Y
Ronald	M	50s	LD	N
Alfie	M	60s	LD/DS	N
Johnny	M	60s	LD	N
Alan	M	50s	LD/DS	Y
Vanessa	F	UNKNOWN	LD/DS	S
Nora	F	UNKNOWN	LD/DS	S
Bob	M	UNKNOWN	LD/DS	S
Maureen	F	UNKNOWN	LD/DS	S
Sid	M	50s	LD/DS	Y
Lizzie	F	70s	LD/DS	S
Doris	F	50s	LD	S
Dominic	M	70s	LD	Y
Horace	M	40s	LD/DS	Y
Martin	M	UNKNOWN	LD/DS	N
Sonia	F	UNKNOWN	LD/DS	S
Bernard	M	60s	LD/DS	Y

* LD = learning difficulty undefined; DS = Down's syndrome

** Y = Yes; N = No; S = Suspected dementia

geographical spread, and types of service provided. Information leaflets and consent forms produced for staff, relatives and service users were used by the service manager and then again by the researchers to discuss the project, address any questions and initiate the consent process.

In each site, it was relatively straightforward to engage with staff through interviews. It was also possible to include a number of service users through focus group or individual interviews. Making contact and engaging with individuals with dementia and their families who were able to take part in this study proved more problematic. Difficulties were compounded by the levels of impairment and the sensitivity of the topic, especially as the formal diagnosis and its disclosure among staff and co-residents was erratic. If the sharing and understanding of

dementia is limited, then the possibilities for undertaking inclusive dementia research are curtailed (Pratt & Wilkinson, 2003). For the 18 people with dementia (or suspected dementia), only three had relatives who could take part. This was partly because a number had no known relatives in touch with them, whilst others had relatives who lived a considerable distance away and were often themselves elderly.

Most of the service users invited to participate expressed a preference for individual interviews; a total of eight service users were interviewed and two focus groups were carried out.

Ethical issues

Throughout this study, the aim was to negotiate consent with all the interviewees

³ All names used in the study are pseudonyms, to protect the identity of the people and places that took part in the study.

themselves. It was also clearly established that consent was an ongoing process repeated as necessary, rather than a one-off event (Hubbard *et al*, 2002).

It was important to ensure that respondents were anonymous and the information they shared was confidential, and names and any details that might identify individuals or organisations are not included in this report.

Study limitations

Within the time and resource restrictions on the study, it was not possible to engage directly with the individuals with learning difficulties and a diagnosis of dementia. However, it was a priority of the study to include a recognition of the experiences, strengths and wishes of people with learning difficulties living in the residential settings with a co-resident with dementia, and of the family and direct care staff caring for someone with dementia. Whilst the study recognises the importance of family care-

giving in this area, the focus on care home settings means that the theme of family care-giving is not explicitly covered and is left as an issue for further research.

Structure of report

The findings are outlined in chapters three to seven of this report. **Chapter three** focuses on the importance of diagnosis. **Chapter four** explores the experiences of co-residents and relatives when someone they know develops dementia, while **chapter five** explores staff perspectives. In particular, chapter five also addresses some specific concerns around eating, night-time support and training issues. Environmental modifications, and pain detection and management are the focus of **chapter six**. **Chapter seven** outlines some key strategies if an individual has to be moved into another care setting. The final chapter draws some conclusions around models of care and outlines some recommendations based on the findings from the report.

Chapter Three

Diagnosis as a starting point

A critical determinant of the journey people take is related to their diagnosis. The availability, timing and management of a diagnosis have a significant influence on the experience of the individual with dementia and the model of care they receive.

A theme which emerged throughout the study was the lack of any standardised tool for the assessment and diagnosis of people with learning difficulties who develop dementia. There was also a clear need for the implementation of explicit care and assessment pathways.

Although there is no 'gold standard' tool or standardised process for assessing and diagnosing dementia in the population of those with learning difficulties, a range of suggested measures and strategies similar to those provided by the American Association on Mental Retardation (AAMR) (1995) have been and are being developed at local levels (Kalsy *et al*, 2000). It was evident from the data in this study that such guidelines were not widely used. Each of the six participating sites had at least one resident whom they suspected of having dementia, yet few of the people in this study had undergone any formal assessment or diagnosis. Such lack of clarity or formality has significant implications for both service development and provision.

The diagnostic process

It is suggested that the keys to initiating and obtaining an accurate diagnosis of symptoms that suggest dementia are located with the

care staff. This process should involve the exclusion of other conditions that may result in symptoms similar to dementia. It is a concern that only one of the sites used a differential diagnostic tool.

It is worth noting that, in a few instances, ambivalence existed amongst a minority of staff about the necessity – or indeed desirability – of obtaining a diagnosis.

Some staff felt that it could be an added burden, as the people were already living with a 'label'. Staff felt that giving an individual another 'label' was unnecessary since they believed that the level of care given to the person would not alter, rather the person would receive 'whatever care was needed'.

When asked about a diagnosis one reply was:

'Would it make any difference?' (Day staff)

And when asked about getting a formal diagnosis:

'No, he's in the middle of a shared assessment to re-assess his needs.' (Manager)

Some staff felt that it didn't matter because, whatever was wrong with the person, they would just continue doing their best for them and dealing with whatever problems arose as and when it was necessary – very much an 'I'll cross that bridge when I come to it' attitude.

For the most part, however, staff recognised the necessity of obtaining a diagnosis. Generally, staff had begun to experience and appreciate some of the obstacles created by not having a diagnosis. When trying to obtain extra staffing hours,

there was nothing on paper to warrant extra help. When staff attempted to get a definitive diagnosis in some places, it proved extremely difficult. This was primarily because no one seemed to know the pathway to be taken to get a diagnosis, and because no one seemed to take the lead responsibility for confirming that the person did actually have dementia. In some sites, it became evident that staff were giving a diagnosis themselves, with no supporting medical diagnosis. Because they were unaware of any appropriate guidelines or route to follow, they would deal with problems as they arose until a crisis situation developed, when they would contact another professional for help (usually the GP).

'We have tried, but nobody definitely diagnosed it...nobody ever said, "he's got dementia".' (Day staff)

'There is nothing in writing to say he has dementia.' (Day staff)

'No one has actually said he has dementia, but we know he has it.' (Day staff)

Staff knowledge and role in obtaining a diagnosis

Clearly, the awareness of staff and relatives of the early indicators will determine the likelihood of someone being considered for a diagnostic assessment, especially where no system for regular health reviews is in place.

It is important to note that when staff were asked to identify changes they felt would indicate possible dementia, those they described were not necessarily the first changes formally known to occur. This would suggest that the condition had often progressed before staff began to see any significance in the changed behaviours, resulting in a delay in the diagnostic management process.

The most frequently quoted signs noticed by staff were as follows.

Shouting:

'He wouldn't stand up or sit down for you, he would shout at you. If you were supporting him having a shower or anything he would shout and scream, and at the end he was hitting out but that was at the end, just before he left.' (Day staff)

Memory loss:

'He couldn't find his bedroom.' (Day staff)

'He's just forgetting things.' (Day staff)

Agitation:

'His routines were disrupted; he would become anxious and worry about things. About having time in the morning to do what he would normally do. He would have his breakfast at night-time to save him time in the morning, plus he would travel, he used to travel independently, he got lost a couple of times.' (Day staff)

'When he was really bad he was violent and shouting and swearing.' (Day staff)

Problems with eating:

'He'd lost the use of forks and knives so we made things for him to pick up with his fingers. We always tried to keep an eye on his diet and when he wasn't eating properly we would give him cornflakes and stuff.' (Day staff)

Where staff had had previous experience of someone with dementia there was evidence that they picked up on the more subtle signs, but this was not always the case.

Staff are unlikely to notice the earliest indicators of change in dementia without training on what these early indicators might be and how to identify them.

This study did not include asking the person with dementia about their experiences. The researchers, however, were able to gain insight into these individual experiences from reports by other people

who lived with them or worked to support them.

The person with dementia

'You could hear him crying in his room and you'd go down and ask him what was wrong and he said, "What's happening to me?". It's as if he knew there was something but he didn't know what was wrong.'

(Day staff)

This is a particularly important observation as it suggests that attentive staff may be able to pick up on the first signs of dementia by listening to what is being said by the person with dementia, rather than waiting for more noticeable physical/behavioural changes.

Staff also quoted examples that suggest the person with dementia can show some awareness of the changes they are experiencing and can be distressed by the consequences.

'What is happening to me?' (Resident)

'Why can't I do this any more?' (Resident)

'It's all going wrong.' (Resident)

It is worth considering, however, that a recognition that something is going wrong and that the person is losing abilities, which may not be addressed by other people in their community, may also be a contributory factor to the onset of depression. The diagnosis of depression may well be an indicator of the onset of dementia (Burt, 1999). This is a complex issue not within the remit of this study, but the coexistence of depression and dementia in people with learning difficulties needs to be part of awareness training for all staff.

As in the general population, people with learning difficulties are likely to be distressed by their loss of control and increasing confusion. These changes may be slight enough in the early stages to be experienced

by the individual, but not sufficient to be observed as significant by carers who have not been made aware of the need to be especially vigilant.

Baseline assessments

Only two sites were conducting baseline assessments with service users at regular intervals. There was direct evidence in one site that this had resulted in the early detection of the condition.

'She [the psychologist] had done the baseline assessment a couple of years previous, then she was called back to redo further tests. It was evident there was a decline by 2001.' (Manager)

This was an important process to enable staff to pick up on changes or deterioration over time, and supported the identification of individuals at an earlier stage. Two of the sites had been able to identify and diagnose dementia through working closely with, and having access to, a consultant with a special interest in learning difficulties and dementia. For many of the services, getting a diagnosis was dependent on geographical location and interested staff, rather than the use of clear guidelines.

'We had baseline assessments on file anyway.' (Manager)

'He was already seeing him for other reasons.' (Day staff)

'We had him diagnosed by his consultant.' (Manager)

'The psychiatrist believed she had the onset of dementia; she has had a scan.' (Day staff)

'The GP is good, he knows about learning disability and even learning disability and dementia, he picks up on things.' (Manager)

At the sites where formal diagnosis had been made, the staff appeared more confident in their dealings with people who developed dementia.

'He has been given a diagnosis [from a psychiatrist]. It's been easier to work with because you know what you're dealing with. It makes it a lot easier.' (Manager)

There are, however, ethical issues around conducting regular assessments. These assessments can be targeted at individuals with an identified risk of the early onset of dementia, and may result in the possibility of others not being given the same opportunities for monitoring and assessment. They also raise the spectre of testing people when there is nothing to indicate they have any need. In a sense, this is a form of discriminatory screening. It has to be done in a way that is understandable and meaningful for the person themselves. It is essential that baseline assessments be incorporated into a general health surveillance programme (Oliver, 1999).

Waiting times

Waiting times were significant in two ways. First, there was often a long delay between staff first noticing signs and the referral for diagnosis. In some sites, staff were picking up on individual signs and changes but the individual was still described as having 'suspected' dementia. Whilst staff were still 'coping' in these situations, the individual was not referred for a more formal diagnosis.

'Everybody gets on and everybody copes very well, the managers manage it, the support staff work it. The staff can be very committed and responsive... that support can increase over time and it doesn't appear a big issue.' (Manager)

Second, even once a referral had been made the process was lengthy and often inconclusive.

'The clinical psychologist thought it was the early onset of dementia. It was a good three years after it started.' (Manager)

'It took around two to three years for them to say he might have dementia.' (Key worker)

In some sites, the staff appeared to readily cope with the changes in the care an individual required. However, this was often the consequence of them giving some of their own time to meet the extra care needs. Making the changes in staff hours that were required as the dementia progressed resulted in negotiations, especially around payment.

Not having a diagnosis can have major implications when applying for extra resources to deal with added pressures on staff working with someone who has dementia. Some staff raised concerns that the progression of an individual's dementia might result in them being moved to an alternative care setting. This could prove to be a barrier to care staff effectively reporting the changing needs of the person with dementia.

Pathways of care

The pathways of care provision that the individuals with dementia followed were varied. Even where a diagnosis was given, there wasn't necessarily any formalised route for the management of the individual's care or any consistent, coherent, systematic or relevant training given to staff.

In one setting with good practice, and where a diagnosis was obtained at an early stage, regular assessments were then conducted with the individual, and the staff were given appropriate training and support.

'Well, we had baseline assessments on file anyway, so the psychologist will keep in touch, its like an annual kind of thing and so there are several of those, the first year or two there were minimal changes and then it became a bit more significant and then the following year it was hard to do the assessment from our point of view.'

(Manager)

Problems of non-diagnosis and non-disclosure

Failing to disclose a diagnosis, whether to co-residents, family, staff or the person themselves, can result in several problems for both staff and the person with dementia. In sites where a diagnosis was not disclosed to other residents or the person themselves, the staff had great difficulty in reassuring the person – it is difficult to discuss dementia if the individual or others do not know about the diagnosis (Wilkinson & Milne, 2003). Examples of this as a problem arose when some people became distressed, knowing something was wrong with them but not knowing what it was. Staff felt that they could not discuss their illness with them. Both ambivalence in relation to diagnosis and lack of knowledge contribute to a lack of dialogue with the person with dementia and lack of consultation with them about their condition, their hopes and expectations, and future planning.

'We couldn't talk to him about it because he hadn't been diagnosed.' (Manager)

Q *'Did anyone tell him what he has?'*

A *'Oh no, I don't think so.'* (Day staff)

Few of the people diagnosed or suspected of having dementia across the sites had been told about their diagnosis. Difficulties around who to disclose to (for example, to other residents or friends of the individual) were also highlighted. Where other residents did know of the diagnosis, there was clear

evidence of them understanding the implications and often being very supportive.

Summary

There is a lack of consistent, clear, coherent practice in relation to diagnosis. What is evident is that this often results in long delays in the identification of early indicators. These delays are compounded by a lack of clear assessment and care pathways and a reliance on 'interested' individual professionals. In two sites there was evidence of signs being noticed earlier, leading to a diagnosis, but this was the result of particular individual professionals being involved and interested.

The regular use of baseline assessments was also significant in earlier diagnosis and this needs to be incorporated into a general health surveillance programme (Oliver, 1999). This should ideally begin from the age of thirty for people with Down's syndrome.

There is a clear need for staff to be better informed about the very early indicators of dementia. Often, their vigilance is crucial in instigating assessment and providing useful information for the practitioner undertaking the diagnostic assessment. Vigilance is also required to exclude other conditions that may be confused with dementia. This is particularly pertinent as an increased awareness of the link between Down's syndrome and dementia can lead to a false assumption that dementia exists. Other conditions must be excluded before a firm diagnosis of dementia can be reached. The use of a differential diagnostic tool designed to alert staff to the range of possible causes of changed behaviours and enable them to make appropriate referrals is recommended (Donnelly & Earnshaw, 2001).

The issue of disclosure is an area for further exploration. There was evidence of differing practice, and of a discomfort around the topic. This may be related to a desire to protect people from the experience of loss

and anxiety. It may also be a difficulty amongst staff and family carers in acknowledging the grief, which is the consequence of living with a person with a condition that begins to change them and makes them seem 'less' than they were.

Findings also highlighted the potential insight of the person with dementia. Whilst not explored in any depth, it is suggested that staff attention to the distress articulated by the person in the early stages may contribute to earlier recognition of dementia.

Recommendations

- There is an urgent need for all staff to receive information and training about the early signs of dementia in the population of those with learning difficulties, and about the issue of differential diagnosis.
- There must be clear guidelines in relation to the development of diagnostic and care pathways.
- There is a need for greater awareness and use of guidelines on baseline assessments. These should be used with people with Down's syndrome from the age of 30.
- There is a need for more research into the experiences of people with learning difficulties with dementia.

Chapter Four

Experiences and issues for co-residents and relatives

This chapter outlines the findings on the issues, experiences, knowledge and attitudes of the people who live with the person with dementia in the residential setting and of the relatives of the people with dementia.

Co-residents

The experiences of other residents were included as part of the study. In any group, the behaviour of one member can greatly impact on the whole group. How the changed behaviour of the person with dementia was perceived and experienced by other people living with them in the home is a key focus of this chapter.

Additionally, how the needs of other people in the group were addressed and the possibility that their needs and responses may have an impact on the model of care available to the person with dementia were considered.

When someone develops dementia in a care home setting, it can have a detrimental effect on the other people they live with. In most sites, staff commented on a high level of acceptance by the other residents of the person with dementia. This tolerance extended to the time staff allocated to the person with dementia and the changes in behaviour of the person with dementia.

'Other residents realised if the workers weren't there it was because they were

looking after R and they made allowances for that.' (Staff)

'He could lie and shout in his bed and be really noisy and he kept her up at night but because she is so fond of him she never complains in a bad way.' (Manager)

'His behaviour was more challenging, mostly it impacted on others.' (Day staff)

Generally, there was an understanding that the person had a condition that caused the changes, and that the person was unable to control the condition and its consequences.

'He couldn't help it, it's an illness.'
(Co-resident)

'Yes it was because of the dementia, he couldn't help it.' (Co-resident)

'There is nothing to be done. He just had the illness. You can't do anything about it. You just get it.' (Co-resident)

'I think his mind was going.' (Co-resident)

In most instances, the level of understanding and tolerance was higher when the reasons for the behaviour or disruption had been explained to the co-resident. It was noticeable that understanding varied depending on the extent to which individuals had been given information. Some places had used the booklet *What is dementia?* (Kerr & Innes, 2001). This had clearly been helpful in enabling people to understand that the person with dementia was not able to control the effects of their illness. People were also

able to demonstrate an understanding of ways in which they were able to support the person with dementia and influence the environment so that it was more acceptable.

'I read him stories about pussycats or dogs.'
(Co-resident)

'I don't shout at him, I try and hug him sometimes.' (Co-resident)

'Don't shout loud at him.' (Co-resident)

'I give him his smelly dog [a toy dog filled with a heated lavender bag]... it keeps him happy, try and help him.' (Co-resident)

Even with a degree of knowledge and understanding, most residents experienced difficulties in certain areas. Some residents would become angry if the person shouted at staff when they were trying to help.

'He would say things like "she is only trying to help you" so it was quite upsetting (the shouting) for them as well.' (Staff)

Anxiety was attached to the levels of noise, particularly shouting and banging.

'Sometimes he just shouted, oh he would shout an awful lot.' (Co-resident)

Q *'What do you think was the most difficult thing about his illness?'*

A *'The shouting.'* (Co-resident)

'Every time people sat him down for his tea he'd start shouting, as if somebody was hurting him, and nobody touches him.'
(Co-resident)

'It upsets me [when he bangs the doors].'
(Co-resident)

Where friction had occurred, it was usually when the behaviour of the person with dementia had become noisy or disruptive, especially at night. Concerns expressed by co-residents included the impact on other residents' sleep of the person waking, and the anxiety this behaviour caused.

'He keeps me awake all night.'
(Co-resident)

'It makes me feel tired, I'm always half asleep.' (Co-resident)

'Worry about him falling down the stairs.'
(Co-resident)

'He wouldn't sleep, he would always get up at night... It wakes me up.' (Co-resident)

'Starts screaming, just screams, wakes all the girls up.' (Co-resident)

Residents also expressed a high level of anxiety around their fear that they or their friends and relatives might develop the illness (see also Wilkinson *et al*, 2003).

'My mum is old. I worry she will get it. I think she will.' (Co-resident)

'Nothing you can do, you just get it. Will I get it?' (Co-resident)

'You get it when you get old.' (Co-resident)

These comments by other residents suggest that there is an understanding of some of the implications of the condition, but that anxiety and distress tend to focus on the disturbing behaviours such as shouting, banging, kicking and, most dramatically, night-time behaviours.

The level of anxiety expressed or demonstrated by other residents was given by staff as a reason for moving some residents to other accommodation.

In summary, it is evident from these findings that other residents have significant reactions to the person with dementia. Their reactions range from fear, annoyance and irritation through ambivalence to acceptance and understanding. To an extent, the response was determined by three factors.

1. The nature of the relationship between the person with dementia and the other residents before the onset of dementia. It is, perhaps, significant that many of the people interviewed had had long-standing

relationships with the people who had dementia. In many cases, people had been friends for over 10 years and sometimes for all their adult life.

2. The level of knowledge and understanding that other residents had of the condition.
3. The severity of the behaviour of the person with dementia. Night-time behaviour, eating problems and violence figured significantly in the behaviours that were most disturbing.

The experiences of relatives

Most of the people in the survey had little or no contact with relatives. Six relatives of three residents were interviewed and the following themes and issues emerged around their anxiety, their gratitude to staff, their lack of awareness and knowledge about dementia, and their desire for more information.

Relatives expressed an anxiety that their relative might have to move from their present accommodation.

'I suppose in a way I would be scared to ask them what's going to happen, because they could say he might be moved into hospital.' (Relative)

'I wouldn't like him to go anywhere else because I don't think that he will get as good a place as this. He's settled.' (Relative)

They also expressed an overwhelming gratitude to staff and a perception that the staff would do all that was possible to keep the person with dementia in the residential unit.

'They're doing a marvellous job. They bend over backwards.' (Relative)

'Well the people in here [staff] I have nothing but respect for them all.' (Relative)

'The staff were simply wonderful. They did everything they possibly could do for him.' (Relative)

There was, however, a general lack of awareness amongst relatives interviewed about the links between Down's syndrome and dementia. There was also little knowledge about the progression of the condition and, in particular, about end-stage issues, until they arose.

Q *'Do you know what happens when someone develops dementia?'*

A (1) *'No, not really, no.'* (Relative)

A (2) *'I haven't followed that up and I would be interested.'* (Relative)

'We didn't know how the dementia affected him.' (Relative)

The relatives often expressed a desire for further information, especially access to leaflets/ books and the opportunity to talk to someone. They asked the interviewer a significant number of questions about the impact and progression of the condition.

'Is it part of the brain that is dying off?' (Relative)

'Why did he get so agitated?' (Relative)

'Why were the stairs difficult?' (Relative)

'He had problems seeing how to go, why was that?' (Relative)

One relative was explicit about definitely not wanting to know about how the condition might progress. It may be that the lack of knowledge amongst other relatives was partly motivated by a fear of finding out, and that staff colluded with this. Certainly, however, the interviewer was aware of people beginning to ask tentative questions. It is possible, of course, that relatives' reluctance to explore further may be linked to anxieties about their own future.

The relatives did not feel excluded from information and decisions about their relative's care but there did seem to be a reticence by both staff and relatives to discuss the progression of the condition and its implications.

The relatives interviewed were all involved and concerned. Despite this, they displayed a lack of knowledge about the condition. Without information about the changing needs of the person as the condition progresses, relatives are restricted in terms of their involvement in making informed decisions about best practice.

Recommendations

- Each organisation needs to have a clear policy on disclosure of dementia.
 - Each organisation needs to develop a policy to support and educate co-residents on the needs of the individual with dementia. This policy should take account of the fact that not every individual with dementia may wish their co-resident to know their diagnosis. The use of person centred planning to support residents to plan for the future, make wills and so on, is an essential part of this policy.
- When giving consideration to the overall management of the care setting, it is important that the additional time requirements to meet the support needs of co-residents are given full recognition.
 - Service providers need to take account of the needs of relatives. Their need for more information about the condition and its progression should be acknowledged. There also needs to be recognition of their need for support.
 - See the *Good practice guidelines in supporting older family carers of people with learning disabilities* produced by the Foundation for People with Learning Disabilities (2003).

Chapter Five

The experiences, knowledge and working practices of staff

The experiences and expectations of staff may be a key determinant in which model of care is chosen: 'ageing in place', progression or 'referral out'. This chapter describes and discusses the experiences of staff in relation to people with learning difficulties developing dementia, the level of staff knowledge and some of the staff responses and adaptations in practice.

Staffing arrangements

Staffing arrangements varied considerably across the six sites. This was the consequence of the different ways in which staff were organised, recruited, trained and managed. Variables such as length of time in the job and degree of attachment were also significant. One site was reliant on a high proportion of bank⁴ staff, while other sites had a proportion of staff who had been in the homes for more than eight years. In one home almost all staff had received appropriate training, while in others there had been little or no training in dementia. Finally, in some homes staff were described as 'part of the family', yet in others it was clear that the staff had a clear home/work life divide. In the site using a high proportion of bank staff there was, perhaps inevitably, a more fragmented service and less attachment between staff and residents.

Whatever the arrangement, an overwhelming experience expressed by staff was of floundering and having to react to changing needs. Few staff had previous training in supporting people with dementia. A few had worked with older people with dementia. Generally, people's experience of dementia was personal, usually gained from caring for members of their own family.

The experiences of staff and their ability to cope are clearly influenced by their level of knowledge and understanding of the impact of dementia on a person with learning difficulties.

The model used will, to an extent, be determined by the staff awareness of the implications for the person with dementia, other residents and the service itself. It is important to note, however, that where good training is given, it has a significant impact on the care pathway of the service users. This is covered in more detail in the section on training.

Lack of knowledge and experience, and uncertainty about what was needed to give best support to someone with dementia, was commonly expressed across all the sites. There was a sense that staff learned as they went along, often at a cost to themselves, other residents and, clearly, the person with dementia. There was recognition that they

⁴ Bank staff are staff employed on a temporary basis, through an agency.

may well be doing the correct things but they had little confirmation of this.

'We couldn't cope with him, I suppose we were novices.' (Staff)

'I know so little about it...I suppose very few of us know very much about how the brain operates, but I'm guessing, really. I'm hoping it's because of what you do... not in spite of it.' (Staff)

'I haven't had any formal training. I think there are some courses coming up.' (Staff)

'He was a learning curve for us because we hadn't experienced... so it must have been going on quite a while before it was said, "right, this isn't Johnny being Johnny".' (Manager)

'Well the staff have been through some pretty rough times with him, to be honest. When he first started with his dementia, I think a lot of it was fear and fear of the unknown, you know, they did not know if we were doing right or wrong really.' (Manager)

The emotional cost to staff

Staff often expressed confusion about what might be the correct care strategies and this became particularly acute when they were concerned that they might be 'failing' the person in some way.

'We can't let another resident die in the hospital.' (Manager)

'I remember we all wanted to keep him here because this was his home and this was where he should be. Saying "we can't support him anymore", I felt really bad.' (Manager)

'If we had not coped, there would have been an enormous sense of guilt.' (Night staff)

The commitment of staff to the people with dementia was clear throughout. This commitment, however, turned into a high cost for the staff. The emotional labour and sense of personal responsibility often meant staff were doing extra shifts or working as waking night staff when they were only officially employed as sleeping cover. This served to mask the level of need, and also placed a burden on staff. Staff would cope rather than ask for help that they feared might result in the person being moved.

'I think sometimes you're frightened to ask for too much because I think if we had pushed at the beginning with M they would just have said, "well we'll need to move him". You are worrying about how much you ask for because we didn't want him to go anywhere.' (Staff)

'We managed because people bent over backwards to manage.' (Staff)

'I would rather be here and have him spend the rest of his days. I get a couple of hours sleep. I can go home and get sleep, my children are off at school. If I can do it for as long as I could and it was possible for him, I would rather him stay here.' (Night staff)

'We didn't apply for it (extra staff from the social work bank staff list) because it was a fear that if we asked for more support they might have said it would be cheaper to go elsewhere.' (Staff)

The level of increased workload motivated by emotional commitment was articulated by a care manager and confirmed in field notes:

'Everybody gets on with it, everybody copes very well, the manager manages it, the staff work it. The staff can be very responsive and their workload increases over time, but it doesn't appear to be a big issue... but if you saw someone with that level of support needs ... the manager would say, "You can't cope with this".' (Care manager)

Staff input increased incrementally so that people took on substantially increased workloads. This was not necessarily acknowledged until the person with dementia was moved to another setting, often to an acute setting, due to a health care crisis. It was at this point that the extent of the workload was revealed by the relaxation in demand. This could make return to the home problematic.

Staff responses

In relation to the first person developing dementia, it was clear that there were two overall responses to meeting their needs within the residential care home settings.

1. The person was moved to another resource. With a single exception, this was seen as a bad thing to do. Staff were left feeling guilty and determined that they would develop skills and expertise so that next time they would be able to keep someone at home, either until their death or until medical needs required a move.
2. The staff struggled to maintain the person at home. This was achieved by changing staffing levels and shift patterns, and seeking increased budgets and some training. There was only one example of a person dying at home. Other residential sites felt they were currently coping and hoped to maintain the person at home.

In terms of staff experience, these two responses are significant. The first, as indicated earlier, often led to feelings of guilt and frustration. The second often resulted from building on the high level of commitment from staff and was not necessarily something that could be maintained over a longer term or for more than one person. The second response led to feelings of triumph and worth but this was at a cost to staff energy, time and budgets.

Key issues that impacted on the staff and residents' experiences

Two key issues that emerged as having a significant impact on the ability of staff to accommodate and support the person with dementia were night-time care needs and issues around eating.

Night-time care needs and coping strategies

People with dementia can often wake at night and may be disturbed, disorientated and in need of, at least, reassurance. The impact on other people in the house of someone getting up at night, walking about, making noise, shouting and turning on lights was frequently referred to.

A key coping strategy to overcome disturbances and meet the care needs of the person with dementia is to have staff who are alert and ready to support the person as soon as they wake up.

The presence of waking night staff was a critical factor in supporting the person to remain at home. The provision positively affected both the experience of the person with dementia and the other residents.

The recognition that people with dementia are going to need extra attention at night, and the consequent provision of waking night staff, was seen as perhaps the most significant change in maintaining people at home.

'I would want H and A to stay here as long as possible. We would have to change our shifts to adapt to people during the night.'
(Staff)

Q *'If you had not had waking night staff would H still be here?'*

A *'No, we went through and are still going through where he's switched day and night... Obviously, he was awake at night so he needed his food and when*

we had two people asleep they were getting up an awful lot to change him.'
(Manager)

'You have to be awake even when he's asleep, you're alert because he's up so quick and he's away... and if he wants the whole house up he shouts, "good morning, good morning".' (Staff)

'When it's night-time... very quiet. There is only you, there are no distractions, there is nobody sitting talking all the time, confusing things around him. There is no TV constantly going on, which is sometimes a good thing for him.' (Staff)

This last point is noteworthy. It underlines the importance of waking night staff. They are not simply there in case of emergencies but have a positive contribution to make to the person with dementia, who may well be better able to receive care and support at night when staff are better able to give focused attention in a quiet environment. This also has implications for training. Often, night staff are not included in training courses, their contribution being underestimated and misunderstood. It is clear from the research that night and day staff require exactly the same training.

Supporting eating and drinking

In the field of dementia care generally, the issue of supporting people to eat well is recognised as a core area for staff training (VOICES, 1998). It is evident that in the general population, over a third of people in care homes are undernourished and dehydrated (Finch *et al*, 1998). Most of these are people with dementia. Indeed, malnutrition rates amongst elderly people with dementia of around 50% have been quoted (Bucht & Sandman, 1990). It is not surprising, therefore, to discover that eating and drinking were issues that figured

prominently in this study. They were areas of concern, tension and conflict.

'Because of his illness, every time, he sat down for his tea he'd start shouting... as if someone was hurting him.' (Staff)

'There are a lot of problems around eating.'
(Staff)

There was evidence in some sites, however, that there had often been useful support, training and guidance from appropriate professionals to help staff. Where a speech and language therapist had been available, good support and advice had been given. There was concern, however, on two counts.

Some staff were not aware that the role of the speech and language therapist was to give advice on problems around eating.

Q *"Have you used a speech and language therapist?"*

A *'No but we don't have a problem with his speech.'* (Manager)

Additionally, access to the therapist was not always easy and one site had no access to a speech and language therapist.

When residents had lost the ability to use eating utensils, staff tried different ways to try and help. This was very much 'trial and error' for the staff who had no training. Staff tried very hard to accommodate the person in their eating habits but had little or no knowledge of how they could help. Field notes record people being left alone to eat, or eating in a busy, noisy atmosphere. Often, very basic and easily rectifiable practices were observed.

'He tries to pick the pattern off the plates or pick things up that aren't there.' (Staff)

This is a good example of a common behaviour to which there is a simple solution, but staff had had no training or advice in a number of sites on the issue of supporting people to eat well.

There were examples, however, of staff making positive adaptations.

'We made things for him to pick up with his fingers.' (Staff)

'We had to puree his food.' (Staff)

'He needs everything liquidised and he needs encouragement.' (Staff)

As the condition progresses and eating becomes an increasingly problematic issue, there are different responses that need to be considered. For example, problems with swallowing increase, the likelihood of pneumonia increases and the possibility of death is faced. Throughout the study, it is noteworthy how often eating was seen as so problematic that when someone was moved to another setting, staff felt the need to visit to support the person with their eating.

PEG feeding – some case examples

This study highlighted a particular dilemma in relation to the use of percutaneous endoscopic gastrostomy (PEG feeding). In particular, two case examples found in the fieldwork highlight some of the issues: Horace, who was advised to have a PEG but staff refused, and Alan, who was given a PEG.

Case study 1: Horace

'Horace always ate. He was eating ordinary food. We were mixing it up a bit before he went into hospital. When they said he was so ill, they got a speech and language therapist to see us. She said it was dangerous to feed Horace, even liquidised food, because it was going down into his lungs.'

'But Horace enjoyed his food in his mouth. He put his tongue out, his mouth open and when he had had enough he shut his mouth and put his tongue away.'

'I gave him ice cream but they said I was pushing it into his lungs. He loved

ice cream and swallowed it well. That was three years ago. He could have gone on a PEG but I didn't see any point in taking the pleasure of food away from him.'

'He does get chest infections a little bit but we have now got the physio-therapist and we have found two antibiotics that actually clear it. The minute we think he is coming down and becoming a bit chesty, we get him on these two.'

'He still swallows and the physio-therapist has shown everybody how to rub him and get as much up as possible.'

'I asked her if she would do a suction if he got bad and she said yes, but he has not got to that point yet.'

Case study 2: Alan

'Alan developed problems with swallowing. We had him everywhere and we pureed his food first of all and that didn't work. Then he ended up in hospital with pneumonia and we nearly lost him. We got him back and then we tried spoon-feeding him. He would have two or three swallowing reflexes and then another teaspoonful. This meant that his mealtimes went on for hours. He would be sitting eating when everyone else was off doing things. He was missing out on the activities in the house and being with his friends. The food would also become unappetising, even with reheating.'

'He then had another bout of pneumonia and again we nearly lost him. His sister asked for a PEG to be fitted. At first, the doctor was reluctant. He said that the use of PEGs was on the decrease because they were not thought to be viable.'

'Alan has been using the PEG for three years now. We only had one episode when he refused to be PEG fed and, again, he was admitted to hospital. But, again, it was due to staff initiative. They put a little backpack on. He didn't like to sit for two hours or so. I think that was what he was rebelling at. Once he was able to have the backpack on and move around, he was just a happy man.

'It is programmed to his special feed. It pumps automatically, so we just plug him in the morning... then he will go on in the afternoon and we'll keep a little bit before he goes to bed at night so he has something in his tummy. The nurse showed us how to do it.

'He doesn't seem to miss having food in his mouth. But he sits with the others at meal times and leaves the dining room with them. He is still part of the group.

'I am certain that, without the PEG, he would have died long ago.'

These two studies illustrate the dilemmas and contradictions involved in this issue of feeding by PEG. The literature available is related to older people in the general population and confirms the dilemmas and ethical issues inherent in the procedure. Many people who are referred for PEGs are frail, and the procedure is associated with complications. Careful management and support for carers is essential. Not all patients benefit from PEG feeding. Clearly, PEG feeding should only be used if it leads to an improvement in the quality of life (Pennington, 2002). Decisions to use PEGs are complex, present a moral dilemma and are further complicated by prevailing politico-economic, social and cultural influences. The use of tubes for artificial nutritional support in people defined as 'vulnerable' is no exception (Mackie, 2001).

The issue of using a PEG is at the extreme

end of a spectrum of issues around supporting people to eat well. Staff need to be aware of the many obstacles to eating well and, more importantly, they need to know how to access advice on ways to overcome the difficulties.

Some interventions and strategies developed by staff

Through trial and error, many of the staff developed ways of coping with problems. Some of these strategies are listed on page 29 as an indication of the type of responses staff were developing, rather than as a conclusive list.

Staff perspectives on training

In highlighting staff perspectives and practice, it is important to recognise the role of training in their work and their preferences for training. This includes the format and delivery of training, as well as the content to be covered. In this section, we report on recurring themes that emerged from each of the sites: the need for appropriate training and the problems associated with little or no adequate training.

There was a dramatic difference between the sites visited in the quality of training received, if training had been given at all. In some sites, no training had been given on people with learning difficulties and growing older, or on caring for someone with dementia. There was little or no evidence in some sites of training about the sort of physical environment that can support good care for someone with dementia. In some sites, staff had had general training on ageing but this had given scant regard to specifics around dementia. Yet in all the sites, staff consistently raised the need for ongoing, appropriate, high-quality training.

There was clearly an issue, not just about whether people had been given training but

Issue	Example of positive intervention
Bathing/showering	<p><i>'He won't sit down in the bath because he can't see the seat, so I usually put a towel over it so it's a different colour.'</i> (Day staff)</p> <p><i>'Let him lie in bed longer, wait 'til the morning rush is over before giving him his shower.'</i> (Day staff)</p> <p><i>'We started showering him when there are two of us, staff would come in earlier so that there would be two of us and not just one.'</i> (Day staff)</p>
Daytime restlessness	<p><i>'Just breaking his day down so that we're not asking him to do more than he can do, just relax him, don't hurry him, just take everything at his speed.'</i> (Manager)</p>
Night-time restlessness	<p><i>'We use the lavender diffuser, I try to put it on before he goes in, there's music for him, it's left on quite low so that if he awakens in the night there's a gentle music going on.'</i> (Day staff)</p> <p><i>'We started using one of the baby monitor things, we could hear him getting up before he came out his room, we could go to help him find his way to the toilet.'</i> (Co-ordinator)</p> <p><i>'I have my nightie and dressing gown on so he knows it is bedtime and he goes back to bed quite happy.'</i> (Day staff)</p>
Environment	<p><i>'We tried lots of different sorts of things, signs on doors, mainly in the early stages when it was still possible for him to get around. He still had more awareness of his environment at that time. So we had signs on the doors, we had special light switches so that lights would come on in certain areas, other lights that you couldn't switch off, so various physical adaptations, nothing tremendously grand.'</i> (Manager)</p>

also about the quality and content of the training. Staff who had not received training felt that getting training was their main priority; in many cases, there was almost a sense of desperation.

'We need training on learning disability and dementia, it's so different from adults with dementia, it really is a different sort of thing. They need to do something.'
(Day staff)

'Our staff are trained for learning disability, they know little about dementia.'
(Manager)

'Everybody is so different. I mean, one of the gentlemen at the minute, his behaviour and the way he sits and eats his shoes, and he's actually one who sits on the floor and we can't get him shifted, and the staff aren't used to that, and we need to know what we're dealing with.' (Day staff)

This underlines the need for staff to be trained before anyone within their service develops dementia. The service needs to be 'dementia-ready' so that staff are aware of the very early signs of the onset of the condition, and for their ongoing ability to cope.

'We need to know what is going on with people, know what to expect.' (Day staff)

'They just really need to know about the more physical aspects of dementia, you look at someone and they look quite normal and you go into the bathroom and you are just hit by a mess which nobody has actually come across before.' (Manager)

Where staff had received relevant and targeted training, there was an appreciable difference in staff confidence, the quality of care and support and the reduction in levels of stress.

'That's what I mean, we were totally oblivious to it and it's amazing how training and being made aware can make a difference.' (Day staff)

'Yes, finding out that even people's social behaviour can change.' (Day staff)

'She really enlightened us about all the symptoms and things of it and a lot of good practice that we didn't know, and this is when everybody thought, "Oh look at all the mistakes we made with J".' (Manager)

'Things even as simple as giving someone a shower or a bathmat, you know how the décor of the place is very important, that you don't know how somebody with Alzheimer's can be... if the flooring is not right they are very hesitant when they walk because it maybe looks like a river to them, how the layout of the room can be very important. Things like not letting them watch some things on the telly because they can't differentiate between what's real and what's not. Looking in the mirror and they don't see a 74-year-old

man, but maybe a 22-year-old. Finding out these things made such a difference.' (Day staff)

Training preferences

Staff were asked how they would prefer to gain/update their knowledge on dementia. Most wanted training courses and reading material, rather than online computer-based or distance learning.

'On-site training and leaflets.' (Day staff)

'In-house training, and backed up with manuals.' (Manager)

'Definitely not on computer, I don't have one.' (Day staff)

'Well I don't use a computer, so it's either reading or talking to people like you.' (Day staff)

'Maybe from other projects that had already dealt with it would have been good if we could have gone to a project and asked, "How did you deal with this?" "What did you put in place?". That, and training for us.' (Day staff)

Summary

This chapter has highlighted the fact that staff were committed to supporting people for as long as possible. Staff were often struggling with a desire to keep the person at home while also being aware that regulations, or simply lack of resources, might cause the person to be moved. There was a clear anxiety amongst some staff that their philosophy and preferred model of support might not be mirrored in either the larger organisation within which they worked or by bodies such as the National Care Standards Commission (England) and the Care Commission (Scotland). This anxiety often led to staff masking emerging needs. There were clear signs of staff not wanting to 'rock the boat'

and make what they saw as perhaps too many demands.

A constant theme that emerged was that there were increased demands, no matter what stage the condition had reached, and that the consequent emotional and physical labour required by staff was often masked until a point of crisis. Whether the level of workload could be maintained in the longer term was a concern for staff.

Of all the sites visited, only one has supported a person at home until their death. Much of the commitment to keep people at home until their death was based on aspiration rather than practical reality.

There was recognition that there were different demands in terms of staffing levels, knowledge and skills, depending on the different stages of the condition (McCarron *et al*, 2002). There was, however, some vagueness and lack of clarity about what these might specifically be.

There was clear recognition, however, that supporting people to eat well and the provision of night-time support were critical to the well being of the person with dementia and other residents.

In relation to the need to support people to eat well, the role of the speech and language therapist (SALT) is critical. There was evidence of good use of this resource in some sites but one site had no access to a speech and language therapist and, across all sites, many staff indicated a lack of awareness around the role of the SALT as an advisor on swallowing and eating generally. This is a training issue, as well as an issue about resources.

In relation to all care issues, there was a noticeable difference in the understanding of trained and non-trained staff towards the needs of the person. Some staff had received training on dementia but this had been focused mostly on the changes within the brain and expected changes in behaviour. Issues in relation to communication and the

experience for the person with dementia had not often been explored in much depth. The training, when given, was also often only half a day.

When asked about their preferred model of training, staff expressed a clear desire for courses that were practice-based and allowed for discussion of current concerns. They also expressed a preference for joint training with people from other organisations, so that there could be a sharing of ideas.

There is, however, a concern that training is given to direct care staff and that managers and service providers who make decisions about resources are not knowledgeable about the needs of people with dementia. The need for other relevant professionals (such as GPs) to be better informed was also evidenced. This is particularly the case in relation to diagnosis, medication, management of 'challenging behaviour' and understanding the experience of people with dementia.

Recommendations

- Staff must have appropriate training.
- A systematic training programme for all organisations providing support for people with learning difficulties who are approaching middle age must be developed. This training must be in place before anyone develops dementia.
- At a minimum the training must cover:
 - what is dementia?
 - differential diagnosis
 - the experiences and realities of the person with dementia
 - communication
 - developing suitable environments
 - maintaining skills and developing suitable activities
 - medication
 - mobility issues
 - pain recognition and management

- supporting people to eat well, particularly issues in relation to swallowing
 - end-stage care.
 - There is a need to develop graduate and postgraduate level courses on ageing in people with learning difficulties to meet the needs of policy makers and professionals who need to have a broader view of the issues in relation to dementia.
 - There is a need for training on issues and strategies in relation to supporting people to eat well.
 - There is a need for easy access to speech and language therapy services and an understanding of the information and skills they can offer.
 - There need to be clear lines of communication between the national commissions and service providers about the philosophy that informs what is seen as 'best practice'
- Service commissioners must be aware of the needs of people with learning difficulties respond flexibly to the fluctuating needs of service providers.
 - Service providers need to be proactive in their negotiations with service commissioners and plan in advance as part of health care planning and person centred planning.
 - Service providers must be aware of the physical and emotional support needs of their staff and respond flexibly to their fluctuating needs, e.g. shorter shift patterns, shared key working responsibilities and the provision of appropriate supervision.
 - Specific consideration needs to be given to the provision of waking night staff at an early stage in the development of the condition.

Chapter Six

Some hidden findings on environmental issues and issues in relation to pain

Two areas emerged as significant, through the general lack of attention paid to them. These were issues of environmental adaptation and pain management, both of which are critical to the care and support of people with dementia. With the exception of one site, where there had been training on the environment, there was little reference to these issues.

Developing dementia-friendly environments

There is clear evidence that people with dementia require 'dementia friendly environments that enable rather than further disable the person' (Judd *et al*, 1998). There are some well-documented features that are core to the development of environments that enable people with dementia, and help them to remain in their own home and familiar setting (Hutchings *et al*, 2000).

With a very few notable exceptions, it was evident that in present accommodation and, indeed, in some instances in proposed accommodation changes, scant attention was paid to the principles of good design for people with dementia.

It was evident that, for most organisations, attention to the environmental needs of people with dementia was restricted to the provision of hoists, special baths and wider doors.

'We had to get a larger bedroom... got a special bed.' (Staff)

'We have got to have a room big enough for a hoist.' (Manager)

Field notes confirmed these observations. Some buildings were complicated in design, with a number of halls, corridors, dark corners and key features hidden from view. There were changes in colour of carpets and shiny flooring in bathrooms. Signage was often not used, and aids to help people find their way were not at a level or type to aid people with dementia. Where staff had received appropriate training, there was a clear understanding of the principles of dementia-friendly environments.

'I think colour is very important because it stimulates and relaxes, so I would like to see that coming in.' (Staff)

'If the flooring is not right they're very hesitant when they walk, because it maybe looks like a river.' (Staff)

'It can be very important, things like not letting them watch the news and things like that because they can't differentiate between what's real and what's not.' (Staff)

'When they look in the mirror... it breaks my heart.' (Staff)

[This is a reference to the fact that seeing a stranger in the mirror frightens people (Kerr, 1997).]

'Like making the toilet door red and things like that, so they know where things are.'
(Staff)

An understanding of the impact of the built environment on the person with dementia is critical to any attempt to provide person centred, appropriate, care. The majority of catastrophic behaviours in people with dementia are induced by the environment as well as by carers (Bawley, 1997). It is therefore important that, as well as being made aware of the impact of their responses, all staff also have an understanding of the dramatic impact of the built environment.

Certainly throughout this study there was evidence of staff responding to behaviours in ways that did not show an understanding that the behaviours were induced by the environment and therefore required an environmental response. Issues in relation to noise, activity level, lighting, colours and signage (Hutchings *et al*, 2000), as well as familiar, predictable and barrier-free environments (Hutchings *et al*, 2000), need to be addressed with some urgency if people are going to be supported to remain in their familiar setting.

There is a need to recognise, however, that some of the necessary environmental changes may cut across the desires and sensibilities of other residents who do not have dementia. The possibility of the home beginning to look less homely is a concern. With the application of good design principles, this would be kept to a minimum.

Where a move to a different care setting is being considered, the environmental needs of the person should be assessed as part of their care needs and included as part of their care plan with decisions taking into account the environmental suitability of the new setting.

Issues in relation to pain management

In the population of older people without learning difficulties, there is a recognised under-reporting – and therefore under-treatment – of pain. As many as 80% of nursing home residents could be experiencing some form of pain (McClellan, 2000a; 2000b). In the community, this figure is between 25% and 50%. Much of this pain is in the joints, limbs and back. Studies on pain also find significantly poor levels of treatment of pain in older people and this under-treatment is magnified in people with dementia (Cook *et al* 1999; Dawson, 1998).

There is no reason to suppose that people with learning difficulties who have dementia do not also experience this high level of pain. The fact that pain can lead to people with dementia exhibiting 'challenging behaviour' such as violence, banging, swearing, spitting and 'wandering' is significant. Staff regularly cited a number of these behaviours, but the possibility that these might be connected with pain was rarely mentioned.

There was, however, one clear reference to the fact that someone might be experiencing pain. This was articulated by a member of staff in relation to a man who was no longer able to move himself and had developed bedsores.

'Well, he is sat down there a lot, we've started putting him on his bed a lot more because it cuts his backside up... he has got sores... it is no good for him to be sat there for hours, the manager has asked me to bring him down again. Personally, I would have left him there to rest his backside. People are there spending time feeding him, but it makes him sore. He has enough to deal with, lets be honest.'
(Staff)

When raising awareness around pain detection and management, it is important

to ask, 'is it enough for staff to treat each resident with tender loving care or should there be an awareness that a certain percentage of the residents may be in pain and that they should be sought out and their pain addressed?' (McClean, 2000a).

On one site, there was explicit recognition of the possibility that the changed behaviour might indicate pain. There was also clear evidence of the issues being positively addressed.

'With somebody else it might have been violent but with B it tended to be a sort of wave of the arm, a sort of angry gesture if you like. It was out of character. It was not the sort of thing he would have done before. He would complain more. It was not clear if that was associated with the dementia or if it was the fact that he was experiencing pain.' (Staff)

'It did take some convincing for the GP to prescribe painkillers.' (Manager)

'The other service which we had which was very useful was from the hospice nurse, she was kind of on hand with advice.' (Staff)

'There was a lot of anxiety about am I doing this right or am I rolling him over in the right way or whatever is it that is causing him pain.' (Staff)

Clearly, pain has to be recognised as a potential issue before appropriate services can be accessed. On the site where pain issues were being positively addressed, they were receiving support and advice from a local hospice.

Summary

The impact of the built environment on people with dementia is well documented. From the interviews held and from field notes, it became apparent that the built environment at the sites visited did not

incorporate established knowledge on dementia-specific design.

Without recognition and understanding of the impact of the environment on people with dementia, staff will probably respond inappropriately to behaviours.

An area for concern is the possibility that people are given medication for behaviours (particularly challenging behaviours (Hopker, 1999)), which could be mitigated by adaptations to the environment.

In contrast, medication may not be given for pain management when it is required. As is the case in the care of people in the general population with dementia, there is a dearth of training in this area. There is evidence, however, that training in pain management does lead to a significant improvement in people's pain experiences (Edwards *et al*, 2001).

There is a large body of literature on dementia-friendly design (Judd *et al*, 1998; Cohen & Day, 1993), and a more limited literature that relates this directly to people with learning difficulties (Hutchings *et al*, 2000; Kerr 1997). This highlights a subject area ripe for cross-fertilisation of learning between the fields of learning difficulties and dementia. The issue of pain management is also an area where it would be profitable to share across the fields.

Recommendations

- There is a need for more literature to be available on the impact of the built environment on people with learning difficulties who develop dementia.
- The impact of the built environment and dementia-specific design features should be incorporated in all training for staff.
- Information and training on this topic needs to be available to architects.
- Care commission inspectors must know about the complexities and dilemmas

in providing dementia-appropriate environments and must become advocates for the development of suitable environments.

- There is a need for more accessible information on how to recognise and manage pain for people with learning difficulties and dementia.
- Core training on dementia and people with learning difficulties should include pain recognition and management.

Chapter Seven

Strategies for providing services when someone has to move

Despite most services expressing the intention to support the person at home, it often appeared inevitable that the person with dementia would be moved. In terms of models of care, this represents a shift from 'ageing in place' to 'referral out'. This section specifically addresses some of the reasons for, and implications of such a move including the issues for staff, the difficulties associated with acute care, the role of staff as advocates and nursing care issues.

Moving on: reasons and implications

The changing needs of the person with dementia led, in a number of instances, to the person being moved to another setting. This was sometimes a temporary move to a hospital and sometimes a permanent move, either to hospital or a nursing/care home for older people.

Decisions about when to move were often dictated by a crisis. Decisions about where to move were often based on available resources rather than a coherent strategy. With only one exception, these moves were seen as detrimental to the health and well being of the person.

Case study 3: Johnny

Johnny lived with nine other people in a residential home for people with learning difficulties. He had lived there for eight years. He was one of the first

residents to move in when the home opened.

Johnny's behaviour began to change. He would become cross and intolerant of other residents. He began to scream for hours. He would wake at night and be in and out of his room, banging doors.

Staff were inexperienced in supporting people with dementia and had had no relevant training. They did not know what to do to help Johnny. In retrospect, they realised that they had continued to respond as they always had and that this was only exacerbating the situation.

Johnny's behaviour became so disturbing for other residents that the decision was made to move him. He became ill and was moved into a general hospital. Staff there had no experience or understanding of the needs of people with learning difficulties. He was put into a side ward and the staff from his residential home had to go in and wash him and feed him, otherwise 'he was left'. If staff from the residential home were unable to go in one day because of staff shortages, the following day they would find Johnny in bed with no pyjamas on, unshaven and his tray sitting beside him. Johnny died 'of starvation':

'...literally it was starvation because if we didn't give him a half teaspoon of water we didn't see anybody else stop by to do it.'
(Manager)

This case study encapsulates a number of significant issues in relation to moving people on.

1. Lack of training and understanding by staff

A reason for moving people was often the consequence of poor levels of staff training. Staff did not understand the significance of changes; nor did they understand the impact of their own behaviour. The sense that they were floundering and learning as they went along is evidenced in the section on staff experiences.

2. Impact on other residents

Another reason given for moving the person was the impact of their behaviour on other residents. Staff were often quite clear about the nature of the impact on other residents and how far this influenced the move.

'It was really the impact on the other residents.' (Staff)

'It really did get to the stage where the rest of the residents were getting agitated, and when the rest of them were getting agitated and crotchety it's like a ripple effect.' (Staff)

It is, of course, important to note that the previous two points may well be related. The lack of staff training may well result in inappropriate responses and a lack of insight into ways of managing the behaviour. This, in turn, will have consequences for the residents.

3. Changes in the level of need

There was a recognition that Johnny's changing needs were making demands that the staff, residents and the built environment were unable to support. One response was to move the person to another setting.

'Basically, we just couldn't manage any more.' (Manager)

'We didn't feel he was getting the care he needed.' (Manager)

Where are people moved to?

People in this study were moved to one of two distinct settings: the acute sector and older peoples' services nursing home provision.

The acute sector

People were moved to hospital at a time of medical crisis. Urinary tract infection, pneumonia, falls and seizures were the most common reasons given.

This was seen as a short-term need, and the staff had originally anticipated that the person would return after a brief stay. There had also been an assumption that the person would receive appropriate care. This was demonstrably not the case, and reflects some of the wider concerns raised about the acute care sector and people with learning difficulties (Hadley & Clough, 1996 – see in particular case study 12).

'She was admitted to hospital with a urine infection, and deteriorated rapidly. I believe that was because the hospital staff were not skilled in working with people with a learning disability... We were majorly concerned. This lady had been put on a side ward. I thought we were going to lose her.' (Manager)

'Her mouth was dry. Nobody bothered with her.' (Manager)

'Because she wasn't making a noise... she could be left and she would die, because they sent for me, claiming that it didn't look very good and I rushed through... but it was because she wasn't getting the attention and I stayed and we all took turns and she improved and came home.' (Staff)

One staff member from the hospital reported to a manager that:

'...she hadn't gone near him because she did not know how to approach him... because he was an adult with a learning disability.' (Manager)

The staff who had experience of going into acute care settings reported having to provide a high level of support to the person moved there. In particular, their role as advocates was highlighted.

Staff as advocates

Despite the move to acute care settings being seen as a short-term event following a crisis, there was a feeling that if the staff did not visit, give help and fight to get the person returned, there was a high risk of the person remaining in the acute setting and not returning home.

'We try to send staff in to support her, but you couldn't have people all of the time.' (Manager)

'We pushed and we pushed [to get her out of the general hospital].' (Manager)

'We go up and feed him and wash him and take clean clothes up.' (Staff)

'When I saw her, I said, "we are going to get her out of there". There is only so much I can do but, nevertheless, we did get her out.' (Manager)

Older people's services and nursing homes

The move to a care/nursing home for older people (sometimes referred in the interviews to as a unit for the elderly mentally infirm/EMI unit) was seen as a permanent, long-term solution, the 'referral out' model of care.

Despite the fact that this was not always at a point of such acute crisis as a hospital admission and more consideration was given

to the move, with one exception this was still considered a negative experience.

'We had a gentleman who lived at home but then he took dementia and he had to go to a nursing home, but came to the day centre here. He was being quite sick after eating so I rang the nursing home and said I was a bit concerned about him after every meal, as he was being violently sick, and they said to me, "but that's all part and parcel of Down's syndrome though, attention seeking behaviour, Down's people regurgitate food" – and his personal hygiene wasn't good when he comes here. The trouble is the staff there have their dementia training but don't know about Down's.' (Manager)

'I regret that I have been involved and asked for a person to be moved to an EMI unit because of the dementia and then a week later realised that this person can't be there. It is inappropriate... They're decades older [the other people].' (Manager)

This finding is an echo of the more extensive writing on this subject by Thompson & Wright (2001).

When someone had been moved, there was clear evidence of this being experienced as a failure by staff. This was even the case where staff had gone to great lengths to try to maintain the person at home.

'I felt really bad about that because this was his home for four years and then all of a sudden you're saying you can't manage him anymore.' (Staff)

Maintaining familiarity

There was also a recognition that simply moving the person from the familiar was something to be avoided. The importance of trying to keep the person with staff and co-residents who knew them well was emphasised.

'People living in residential homes being admitted to a general hospital and they never set foot back in the home again and they lived there for 10 years. How sad is that for the person, especially if the dementia is causing the individual issues about being away and from people who know them and the security.' (Staff)

'He went to X [general hospital] last time. I wouldn't want to see him going back and live out his last years up there because of the environment he's been in here. To actually go into somewhere like that. I don't think he would adapt to it because it is a big place and this is familiar surroundings. This is his home. He might not know our names but he knows our faces. He knows his bedroom, he has a routine.' (Staff)

Nursing care issues

A reason given for moving people was the development of the condition to the point where the person required 'nursing care'. People were concerned that the care standards could mean that the person had to move to another setting for nursing care. This was often accompanied by a recognition that the move was not necessarily going to provide more appropriate care.

'I would like it if it were picked up earlier, that they're not stuck in nursing homes where they are going in and instead of having one disability they're getting two and the staff in the nursing homes are not trained to look after people with Alzheimer's, so how can our client group be looked after? They are put in there to die, they last about two to three months and that's it. It is hard when you look after someone for 10 years, to give them into someone else's care who will not give them the care they need.' (Manager)

'Well if they needed nursing care they might draw the line and say this gentlemen or

lady needs nursing care, you are not a nursing home, because the Care Standards Commission would not allow us to do nursing care.' (Staff)

'If they needed general nursing care then we would have to say we can't look after them; W is a trained nurse, I am, but we are not allowed to practice it here... so then they would need to go into a home.' (Manager)

'It's a residential home and its almost as if they do not want to go beyond that. Community care... tick the boxes with residential or nursing and that's what it is going to be.' (Staff)

'The manager says, "We are not managing, it's not working. This person needs to be moved. This person has a diagnosis of dementia, they need to go to an EMI unit specially for dementia," imagining there is something out there that exists which is... for people with a learning disability and dementia... they don't exist.' (Care manager)

There were clear responses to the recognition that people needed to be accommodated either within the present home or in a more appropriate setting designed to better meet their needs.

'If you actually thought about this, to move somebody from a residential setting to a nursing home to give them 24-hour support, why not pay the extra money to give 24-hour support in the residential home? The system doesn't like that and it is as if they do not want to go beyond that.' (Care manager)

'If we got the right package together with the right kind of members of staff, being temporary, nursing, district nursing. We've done it before with other people.' (Manager)

The evidence for the need to accept the imperative to provide nursing care within

the home was demonstrated fully by the experience of one organisation that kept the person at home and nursed him until he died. The staff in this residential unit were not nurse-trained but community resources were used and staffing levels increased.

Interestingly, the one move that was seen as positive was where the staff recognised that the person was moved to somewhere where there were trained staff who also had nursing qualifications. It was significant, however, that it was the level of support and stimulation that R received that was seen as most important. In addition, the calm atmosphere of the place was cited as a contributory factor to his well being.

It was noted by all staff, and especially the manager, that the reasons for the move were related to staffing levels and that nursing care was not the primary reason for the move.

'If we had more resources, R would still be here.' (Manager)

There was also recognition of the critical role of training on staff ability to keep the person at home. Many staff were able to cite the direct application of learning from training and how this helped them to understand behaviours, change response and therefore reduce the need to move the person.

Summary

The evidence within this section overwhelmingly suggests that staff, managers and indeed service providers and purchasers are committed to the idea of supporting people to 'age-in-place' (Janicki & Dalton, 1999a). It is significant, however, that with one exception, none of the organisations had experienced providing end-stage care. Whilst people expressed the desire to keep people until their death, there was also a worry, and in a few cases a recognition, that if the person required nursing care they might be 'referred

out' (Janicki & Dalton 1999a). Although past experience had demonstrated that such moves were often detrimental to the well being of the person with dementia, the intention was that the move, if it did occur, would be at a later stage when the person 'did not know what was happening'. The overwhelming commitment to keeping people at home meant that staff were often crossing boundaries between work and private life, and were using high levels of emotional commitment. It is significant that in the setting where the man with dementia was kept at home, the manager was not sure if this could be maintained if more than one person developed dementia within the unit at the same time, or if people developed the condition in quick succession.

What was also clear from the study was that when people did move on, this was not usually for positive reasons. There was a sense in which it was a move to somewhere else because the present placement was not working. There was no guarantee that the new placement would be any better equipped or able to meet the needs of the person with dementia. The move to another setting, while improving the situation for other residents, did not necessarily benefit the person with dementia. This was substantially because the staff in the new placement, the acute or generic services, were inexperienced, and lacked training in working with people with learning difficulties, or even dementia.

Recommendations

- Staff in nursing homes and in hospitals must receive appropriate training on both the needs of people with learning difficulties and on dementia.
- People should not be moved to a resource unless it is evident that staff have had the appropriate training.

- People should not be moved to settings that do not provide an environment that meets the needs of the person with dementia.
- Care managers must ensure that, when people are moved, the new care setting meets at least basic criteria for good dementia care.
- Service commissioners must develop flexible and responsive financial systems which acknowledge the rapidly changing care needs of someone with learning difficulties and dementia. Service providers should not have to keep applying for additional money and then wait long periods while this is processed.
- Services for people with learning difficulties need to anticipate the needs of an ageing population, and particularly people with dementia. The services need to develop a coherent strategy that does not rely on ad hoc arrangements that result in people being moved to inappropriate placements.

Conclusion

Models of service delivery

This project set out to explore some of the models of care experienced by people with learning difficulties and dementia. It sought to identify the nature and impact of these models of service delivery and to make explicit the implications for the person with dementia, co-residents, service providers, their staff and service commissioners.

The model used to inform the project was that described by Janicki & Dalton (1999a) as set out below.

1. 'Ageing in place', where they remain in their own accommodation with appropriate supports adapted and provided.
2. 'In place progression', where staff and the environment are continually developed and adapted to become increasingly specialised to provide long-term care for the person with dementia within the residential service (but not necessarily their own accommodation).
3. 'Referral out', where they are moved to a long-term nursing facility or other type of provision.

We now examine these different options within the model in the light of the experiences of the six sites in this study.

Option A: 'Ageing in place'

The first option to maintain people to 'age in place' was one that all of the places visited were endeavouring to pursue. However, only one site in the study had supported a person

with learning difficulties through their dementia to death. This site drew on a number of sources to achieve this.

1. The use of a large, trained and supervised team of volunteers which was available to supplement paid staff.
2. The volunteer team supported the co-residents who did not have dementia. This enabled the paid staff to provide dedicated time to meet the needs of the person with dementia.
3. The introduction of altered shift patterns to manage the person with dementia's needs over the 24-hour period and to accommodate the increased pressures placed on staff.
4. Incremental financial support from the local authority to cover the cost of additional paid staff to compensate for the alterations in shift patterns.
5. Substantial adaptations to the environment.
6. The use of significant medical supports, which included the use of learning difficulty, hospice and district nursing services and positive support from their GP.

Only one person with dementia was supported at this site. It is noteworthy that the manager had concerns about the feasibility of maintaining this model if there had been more than one person with dementia at the same time or a quick succession of people with the condition.

Option B: 'In place progression'

The research project did not observe any completed examples of 'in place progression'. In one site, however, a decision had been made to develop an 'in place progression' model. In this setting, it was proposed that a house be built in the grounds of the present accommodation, connected by a corridor. The new building was designed to incorporate many of the features recommended in the literature. All staff had received specialist training on supporting people with learning difficulties and dementia. The easy access between the two houses was seen as critical, as it allowed staff and residents to maintain regular contact.

The intention is that staff should work in both houses. This would have two positive consequences.

1. All staff would develop expertise in working with people with learning difficulties and dementia.
2. These staff, while developing expertise, would have breaks from supporting people with learning difficulties and dementia. They would, therefore, be relieved of some of the pressures associated with this work.

This house could be used as a placement for people with dementia from other learning difficulty services. While this still places the service within an 'in place progression' model, it does reduce the important aspect of familiarity (Kerr, 1997) for people moved into the service from outside.

Option C: 'Referral out'

This option was one that most sites had experienced. Within this, people were 'referred out' to hospitals and care/nursing homes for older people. With one exception, this was seen as a negative experience. It is useful to consider those aspects of the

exceptional experience which were identified as positive.

1. The new setting had expertise in supporting people with learning difficulties and was informed about the needs of people with dementia.
2. It was seen as a direct improvement on the original site.

The manager and staff of the original site stated that, with appropriate changes to their environment and to staffing levels, the person might have been able to remain in his original home. In particular, they identified the need for the use of waking night staff.

In general, 'referral out' was viewed as a detrimental experience. The finding of this report is that, in general, 'referral out' is not appropriate. It should be noted, however, that when 'referral out' cannot be avoided, then meeting the following criteria in the new site can be important.

- Staff have appropriate training on the needs of people with learning difficulties and dementia.
- The built environment meets the needs of people with dementia.
- Contact is maintained with the original staff and co-residents.
- The move is planned in advance.
- The person moves with an appropriate person centred plan and relevant information such as that contained in life story work (Hopkins, 2002; Kerr, 1997).

Outreach as a model

This did not exist in any of the sites. This model would use resources external to the residential service. It would provide additional support to maintain the person in their own home. An outreach model could be delivered through a coordinated service provided by designated staff in the locality, such as within a social work centre or a

community learning difficulties team. This provision could incorporate the following elements:

- the provision of extra support staff for the residents without dementia; this would release staff in the home to give time to the person with dementia who they know and who know them
- the use of palliative care services
- the use of other professional expertise, such as speech and language therapy
- the availability of staff to give general advice and support on dementia
- the provision of good-quality, specific dementia respite care.

Conclusion

The data from this study suggest that there is no single perfect model of care. It is clear that each option or model presents problems and dilemmas. The complexity of the needs and demands associated with supporting people with learning difficulties and dementia in care home settings means that, at the moment, all three options and a combination of aspects of each model will continue to be used.

People will continue to be moved from their home setting. Where this happens, attention needs to be given not only to *where* the person is moved but also to *how* the move is managed. Too often, the person moves abruptly and co-residents and staff lose contact. This has a detrimental effect on everyone involved in the process.

When a move is made, it is essential that everyone of significance to the person being moved is involved and contact is maintained. It is also critically important that staff in the new setting know as much as possible about the person they are caring for. The use of life story work should be an integral part of this process (Kerr, 1997).

The need for managing the *how* as much as the *when* and *where* implicit in the models needs to be given more importance.

The number of people with learning difficulties who develop dementia is going to increase significantly (Holland *et al*, 1998). With the resultant increased pressure it is imperative that service providers develop more imaginative and responsive ways of supporting people, no matter which model is used.

Overall recommendations

Training

- Staff must have appropriate training.
- A systematic training programme for all organisations providing support for people with learning difficulties who are approaching middle age must be developed. This training must be in place before anyone develops dementia.
- At a minimum the training must cover:
 - what is dementia?
 - early signs
 - differential diagnosis
 - the experiences and realities of the person with dementia
 - communication
 - developing suitable environments
 - maintaining skills and developing suitable activities
 - medication
 - mobility issues
 - pain recognition and management
 - supporting people to eat well, particularly issues in relation to swallowing
 - end-stage care.
- There is a need to develop graduate and postgraduate level courses on ageing in people with learning difficulties, to meet the needs of policy makers and professionals who need to have a broader view of the issues in relation to dementia.

Assessment and diagnosis

- There needs to be attention to the development of consistent assessment tools and procedures.
- There must be clear guidelines in relation to the development of diagnostic and care pathways.
- There is a need for greater awareness and use of guidelines on baseline assessments. These should be used with people with Down's syndrome from the age of 30.
- All staff must receive information and training on the early signs of dementia. They must also understand the importance of differential diagnosis.
- Services must have a policy and guidelines on the disclosure of dementia.

Meeting the needs of co-residents and relatives

- Each organisation needs to develop a policy to support and educate co-residents on the needs of the individual with dementia. This policy should take account of the fact that not every individual with dementia may wish their co-resident to know their diagnosis. The use of person centred planning to support residents to plan for the future, make wills and so on, is an essential part of this policy.
- When giving consideration to the overall management of the care setting, it is important that the additional time requirements to meet the support needs of co-residents are given full recognition.

- Service providers must take account of the needs of relatives. Their need for more information about the condition and its progression should be acknowledged. There should also be recognition of their support needs. Refer to the *Good practice guidelines in supporting older family carers of people with learning disabilities* produced by the Foundation for People with Learning Disabilities (2003).

Access to specialist services

- There needs to be an increased awareness of the role of specialist services.
- There is a need for easy access to speech and language therapy services and an understanding of the information and skills they can offer.
- Palliative care support and information from relevant bodies must be incorporated into care and service plans.
- Access to physiotherapy and occupational therapy services should be maintained.

The built environment

- The impact of the built environment on people with dementia must be recognised and incorporated into all buildings for people with dementia.
- There is a need for more literature to be available on the impact of the built environment on people with learning difficulties who develop dementia.
- The impact of the built environment and dementia-specific design features should be incorporated in all training to staff.
- Information and training on this topic needs to be available to architects.

Pain issues

- There is a need for more accessible information on how to recognise and manage pain in people with learning difficulties and dementia.

- Core training on dementia and people with learning difficulties should include pain recognition and management.

Issues for managers and commissioners of services

- Service providers need to be proactive in their negotiations with service commissioners.
- Service providers must be aware of the physical and emotional support needs of their staff and must respond flexibly to their fluctuating needs, for example by arranging shorter shift patterns and shared key working responsibilities, and by providing appropriate supervision.
- Priority needs to be given to the provision of waking night staff at an early stage in the development of the condition. It appears to be a significant determinant of whether people move to another setting or remain at home.
- Service commissioners must develop flexible and responsive financial systems which acknowledge the rapidly changing care needs of someone with learning difficulties and dementia. Delays in funding often lead to lack of appropriate support throughout the course of the condition.
- Services for people with learning difficulties need to anticipate the needs of an ageing population, and particularly people with dementia. The services need to develop a coherent strategy that does not rely on ad hoc arrangements that result in people being moved to inappropriate placements

Specific issues for the care commissions

- There need to be clear lines of communication between the national commissions, service providers and local commissioners about the philosophy that informs what is 'best practice'.

- Care commission inspectors must know about the complexities and dilemmas in providing dementia-appropriate environments, and become advocates for the development of suitable environments.

Issues when people are moved to a new setting

- When people move to another setting, attention must be given to how this is carried out. In particular, staff and other residents need to be involved.
- Contact must be maintained.
- Staff in nursing homes and in hospitals must receive appropriate training on both the needs of people with learning difficulties and on dementia.
- People should not be moved to a resource unless it is evident that staff there have had the appropriate training.
- When people are moved, care managers must ensure that the new care setting meets at least basic criteria for good dementia care.
- People should not be moved to a setting that does not provide a built environment that is suitable to meet the needs of the person with dementia.

Recommended further work

- Further research is needed into the experiences of people with learning difficulties and dementia.
- Training resources and courses on the needs of people with learning difficulties as they age need to be developed. These should specifically address the needs of people with dementia.
- Issues in relation to learning difficulties and dementia should be integrated into relevant professional courses.
- Easily accessible literature should be developed on the role of the built environment. Examples of principles and good practice should be provided.
- Research is required on the impact and prevalence of pain in people with learning difficulties and dementia. Research is also required into the understanding and responses of staff to this issue. Guidelines should be developed on this issue.

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