

**Services for People with Dementia
in Wales**

2001-2002

Report No.1.

Residential and Nursing Home Care

Dementia Services Development Centre Wales

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EXECUTIVE SUMMARY

This report from DSDC Wales is the first of a series of ‘snap-shots’ of service provision for people with dementia in Wales, arising from a Service Mapping project funded by the National Assembly for Wales. It focuses on analysis of information relating to residential and nursing home care for people with dementia. This is timely in view of the substantial changes currently occurring in this sector. It is also an area not addressed in detail by the Audit Commission in their recently completed report on a nationwide audit of services for older people with mental health problems in Wales, ‘Losing Time’.

The report is based on returns from 235 residential and nursing homes from all parts of Wales, providing care for over 6000 residents. This sample approximates to 30% of the over 65 residential care population in Wales. The majority of homes were in the independent sector, with a quarter operated by local authorities. Nearly half (48%) of the residents were reported to have a dementia; two-thirds of these were considered to have a moderate or severe degree of the condition. Only 21% of places were allocated specifically for people with dementia.

Residential and nursing homes are a major and vital component of service provision for people with dementia. Homes reported offering a wide range of services, therapies and activities, and a number of examples of good practice were evident from the returns made, despite the many pressures currently facing homes. There are some key areas where further support could be provided to homes to assist them in providing a higher quality of service; for example, specialist services could work more closely with homes, and more support given for staff training.

A quarter of care staff are currently trained to NVQ level 2 or above, compared with the National Assembly’s target of 50% of such staff to have attained this qualification by April 2005. Only 10% of homes met this target in this survey. When those in

training at the time of the survey are taken into account, over a third of homes would continue to fall short of the target by some distance.

The major conclusions of the report are as follows:

1. **All homes for older people need to have expertise in providing care for people with dementia.** Homes in this sample estimated that 48% of their residents had dementia, and previous research indicates this is likely to be an under-estimate of the total figure. Some homes might usefully specialise in providing care and support for those with particular difficulties, such as challenging behaviour, but the general principles of person-centred dementia care need to be universally applied.
2. **Training in dementia care needs to be more widely available.** This has implications for the general training of staff, and further support would be helpful to develop new models for the delivery of training to the large numbers of staff involved, as well as for the expansion of existing models. A strong dementia care component to NVQ type training is essential to take this forward.
3. **Specialist mental health services for older people have a role to play in developing a more proactive approach** to the support of residents in homes, recognising their key role in the spectrum of services. This needs to go beyond training, to include the encouragement of a positive care culture, which can prevent some crises and manage problems in a less restrictive setting.
4. **Appropriate services for younger people with dementia in Wales are under-developed.**
5. **Families could be involved more fully in homes,** to work in partnership. This is a particular priority in dementia care, where many families continue to experience emotional strain after their relative has been admitted.
6. **Therapeutic activities suitable for people with severe dementia need to be encouraged.** The focus tends to be on people with dementia with mild or moderate impairment and there is a need to develop and use a wider range of approaches and interventions, including forms of stimulation such as music, aromatherapy and massage.

1. Background

1.1: The Dementia Services Development Centre Wales is a partnership between the University of Wales, Bangor and the Service Development Team (EMI), Cardiff & Vale NHS Trust, and forms part of the UK wide network of such centres. DSDC Wales has been operational since August 1999, providing information and resources for service providers and encouraging service development. The Centre also offers training and conducts research into dementia care.

1.2: Requests for information regarding services for people with dementia and their supporters are regularly received by DSDC Wales, and in November 1999 the National Assembly for Wales agreed to fund the establishment of a database to collect together as much information as possible on such services. This would serve to increase the information resource available to service providers, planners and commissioners.

1.3: The database has now been established, and enables detailed information on the whole range of services for people with dementia and their supporters to be collated. Like any database it is reliant on the information provided by service providers and this places limits on its accuracy and the comprehensiveness of its coverage. However, it is a dynamic electronically based system that will allow for responsiveness to service changes and developments. Now the framework is in place, there will be a continual endeavour to up-date the database and extend its coverage and usefulness.

1.4: The database allows an analysis of services by service type and by area of the country, and these analyses may prove useful in identifying areas of good practice as well as areas where there is a need for service development. Each analysis provides a snap-shot of services at a moment in time, which may enable changes in service provision to be tracked in years to come. The first in a series of such analyses has been undertaken on residential and nursing home care for people with dementia and forms the subject of this report. This is timely in view of the substantial changes currently occurring in this sector. It is also an area not addressed in detail by District Audit in their recently completed nationwide audit of services for older people with mental health problems ('Losing Time'; Audit Commission, 2002).

2. Residential and nursing home care and dementia

2.1: Today, there are almost half a million older people who live in nursing and residential care homes in the United Kingdom. A compilation of official figures suggests that approximately 21,000 people over the age of 65 in Wales were resident in such a home as at 31st March 2000. This constitutes approximately 4.2% of the population over 65, compared with an estimated 4.8% for the UK as a whole. Over 125,000 older people in receipt of nursing and residential care are in privately operated residential and nursing homes in the UK (Royal Commission on Long Term Care, 1999). In Wales, 20% of residents are in Local Authority homes, although an estimated 53% of residents in independent residential and nursing homes receive Local Authority support. Factors including increased life expectancy, chronic health problems, changes in family structure and the frailty of older carers indicate that the demand for admissions to nursing and residential care is likely to rise, unless there are dramatic changes in community support available. Wittenberg et al. (1998) estimated that between 1995 and 2031 the numbers of older people entering nursing and residential care could rise by an average of 64%. At 31st March 2000, a total of 4702 beds in residential and nursing homes in Wales were vacant (16% of the total); Local Authority homes showed the lowest vacancy rate (11%), whereas independent sector nursing homes reported a rate of 19%. Reports of home closures are becoming widely known, with problems in staff recruitment increasingly challenging the economic viability of homes. UK figures (PSSRU, 2002) suggest an overall annual 5% rate of closure for independent care homes. If there has been, in the past, over supply of residential placements, this does not appear to have applied to homes specialising in dementia care, where clinicians report places being insufficient in half the areas of Wales, and individuals being placed as far as 50 miles from their homes (Audit Commission, 2002; pp. 33).

2.2: Deterioration in cognitive functioning, as found in dementia, is invariably seen as a significant risk factor implicated in entry to nursing and residential care. For example, Mozley et al. (1999) found that two thirds of older people newly admitted to nursing and residential care homes had severe cognitive impairments. There are estimated to be 700,000 people with dementia in the UK with 40,000 living in Wales (Alzheimer's Society, 2002). Many people with dementia will, at some stage, require residential or nursing care. A recent study of nursing homes in the South East of

England *not* registered for the care of Elderly Mentally Infirm residents (Macdonald et al, 2002) indicated that 74% of residents of such homes had probable clinical dementia. It has been argued that 'dementia care has become the main business of almost any residential or nursing home for older people' (Macdonald & Dening, 2002).

3. Service mapping project

3.1 The survey sample

The data on which this report is based comes from a postal survey of care homes in Wales conducted in early 2001. Care homes throughout Wales were identified from lists maintained by Social Services and Health Authorities. Where it was clear that homes did not provide care for older people or people with dementia, these were excluded at this stage. Key personnel from each care home were identified (usually the care home manager) and were invited by letter to complete a questionnaire. The survey consisted of a comprehensive questionnaire designed to gather information about several key areas including:

- Demographic information on the service users with specific reference to people with dementia
- The type of service currently provided by care homes
- Operating details, including the various facilities offered by the homes
- Staffing characteristics and staff training
- Information relating to carers of people with dementia

A total of 930 questionnaires were distributed to nursing, residential and dual registered homes. There were 235 returns representing a response rate of 25%. The total number of residents included in the sample was 6332, equivalent to 30% of the over 65 population in residential and nursing homes. The average number of residents per home was 27, much larger than the average adult care home residency in Wales (18), perhaps suggesting that homes for older people tend to be larger than homes for other adult client groups, and that larger homes were more likely to respond to the survey. There were estimated to be 603 people on waiting lists for entry to the nursing and residential care homes in the sample surveyed, representing nearly 10% of the

current residential population. Of the 84 homes that stated they had a waiting list, 66 were in the independent sector.

3.2: The homes in the sample

The geographical location of the care homes in the sample is shown in Table 1.

North Wales	Mid Wales	South Wales
n = 99	n = 16	n = 120

Table 1: The geographical distribution of care homes responding to the survey.

Responses were received from homes within each of the local authorities in Wales. However, it was notable that some of the larger authorities were under-represented.

Care homes were classified by service type: nursing, residential or dual registered. Over half of those who responded were residential care homes. The percentage in each category is shown in

Table 2.

Nursing	Residential	Dual registered
25%	60%	15%

Table 2: Classification of care homes in the sample

35 homes (15%) were described as dementia specific. Of these 13 were residential homes, 13 were nursing homes and the remaining 9 were dual registered.

“We tendered for EMI beds, but our local social services ignored our offer, hence we abandoned the idea.”

“We have more facilities but XXX Social Services will not pay more for EMI care.”

“We try to keep our elderly clients with us for as long as we can. The families receive support and the facilities for EMI patients in this area are not good. While the patient is manageable we can cope – in 6 years we have only transferred 2 patients whose behaviour became unacceptable.”

Details regarding the operation of the care homes in the sample are shown in Table 3. Ten homes were operated by more than one provider. However, in the majority of cases the independent sector was involved in the operation of the home. 82 homes stated that they operated as part of a chain with an average of 11 homes involved in each chain. A quarter of homes in the sample were operated by Local Authority Social Services departments, rather higher than the 16% of homes in Wales falling into this category.

	Percentage of homes
Health Service	3.5%
Social Service	25%
Independent sector	71%
Voluntary sector	1.5%

Table 3: Operation of nursing and residential care homes

Nursing and residential care homes were asked to provide details of any age criteria for entry to the home. 32% stated they had no age criteria, 52% admitted only those over 65 years of age, 4% specialised in the care of the over 70's and the remaining 12% focused exclusively on those over 75 years of age.

3.3: Dementia in homes

Respondents were asked to provide details on the numbers of people who they considered to have dementia. In addition, they were asked to consider the degree of dementia (mild, moderate or severe) based on guidelines provided in the questionnaire. The total number of residents believed to have some form and degree of dementia was 3032 (48%). The percentages of residents assessed by key personnel to have each of the differing degrees of dementia within the nursing and residential home population sample are shown in Table 4.

Percentage of total residents reported to have dementia	48%
<i>Degree of dementia, as percentage of those reported to have dementia</i>	<i>Percentage</i>
Mild	34%
Moderate	36%
Severe	30%

Table 4: The percentages of residents considered to have different degrees of dementia

Thus, it was reported that nearly two-thirds of those people thought to have dementia were considered to have a moderate or severe degree of the disorder. Table 5 shows the proportion of total residents in each type of home reported to have a dementia, and the breakdown of severity by type of home.

Degree of Dementia	Residential Homes	Nursing Homes	Dual-registered
Mild	36%	19%	35%
Moderate	38%	34%	32%
Severe	26%	47%	34%
Proportion of total residents reported to have dementia	44%	61%	47%

Table 5: The percentages of residents in different types of homes reported to have different degrees of dementia

A greater proportion of residents in nursing homes are reported to have a dementia, and the majority (61%) of these are said to have a severe dementia. Residential homes have a significant proportion (over a quarter) of residents with severe dementia; because this is the largest of the three sectors, this represents a substantial proportion of the total numbers of residents reported to have a severe dementia. Only 7 homes

(3% of the total) responded that they did not have any residents with dementia at all: these were all residential homes. Six out of seven of these homes had no dementia beds, the remaining home had 11 beds designated for people with dementia that were not currently in use by people with dementia.

“Our policy is to maintain the client in our home regardless of the deterioration. Clients admitted with no evidence of dementia, or with mild dementia, often progress over the years to moderate or severe dementia.”

“We have a variation in registration for people who develop dementia while at our home.”

“The home is not registered to accept residents with dementia. Many are confused (36/58), but not considered as having dementia.”

“Our home is for general care only. People who are EMI (*Elderly Mentally Ill*) diagnosed are not within our registration category, and are unable to be admitted. Those with dementia in-house have medical problems which over-ride their psychiatric needs.”

“This home was never designed to cater for people with dementia. However, the vast majority of social work referrals we receive are for individuals with dementia. The inspectorate expect us to be in the straightforward category of ‘elderly’. They are still employed by the same local authority as are the social workers.” (35 residents all with dementia)

3.4: Balance of permanent and respite places

Questions were asked regarding the number of beds designated for specific care purposes. Residential and dual registered homes provided a possible total of 4200 beds for residential care. A detailed breakdown of the number of beds available for people with dementia and beds for respite care is shown in Table 6. The proportion of beds allocated specifically for dementia falls far short of the number of people with dementia in the residential population.

Type of Bed	Percentage allocated from total
Residential beds for people with dementia	21%
Residential beds for respite care	3%
Respite beds for people with dementia	1.5%

Table 6: The percentage of beds available in residential and dual registered homes designated for dementia and respite care

It is noteworthy that very few beds were designated for respite care, and even fewer were designated specifically for respite care for people with dementia. Respite care has been shown to extend the duration of community living (Levin et al., 1994) although it can also be disruptive for the person with dementia (Moriarty & Webb, 2000). It is likely that the low figure found here reflects the current difficulty in funding respite care provision and the need for the independent sector to maximise the amount of secure funding available.

Nursing and dual registered homes provided a potential total of 3810 beds for nursing care. A detailed breakdown of the number of beds available for people with dementia and beds for respite care is shown in Table 7.

Type of Bed	Percentage allocated from total
Nursing beds for people with dementia	21%
Nursing beds for respite care	0.4%
Respite beds for people with dementia	0.2%

Table 7: The percentage of beds available in nursing and dual registered homes designated for dementia and respite care

Again, the proportion of beds allocated for dementia does not approach the number of people reported as having dementia. The number of respite beds available is again very small and may mean that respite care has to be provided in a hospital setting for a person with dementia living in the community who requires nursing care. If an extrapolation were to be made from this sample, this would suggest perhaps 30 nursing home designated respite beds for people with dementia across the whole of Wales, with perhaps another 250 in residential homes.

3.5: Day-care in homes

More positively, respite in the form of day-care for non-residents with dementia was available in 99 homes (42%). This is a welcome finding as it indicates a link between the homes and the wider community and may enable a person with dementia to become familiar with the home by attending for day-care prior to entering the home.

3.6: Interventions and activities available in homes

Care home managers were asked to indicate the interventions available to people with dementia and their carers. On the medical front, about three-quarters of homes mentioned the monitoring of medication, with about 10% having residents on the relatively recently licensed anti-dementia drugs.

“We are working towards a tranquilliser-free environment.”

Assessments included those involving the carer and the care recipient. Under a third of nursing and residential care homes formally assessed cognitive functioning. Over half of the homes stated that they conducted interviews with the carers but less than 20% reported provided counselling for carers and patients. A more detailed analysis of support offered to carers can be found in Section 3.14.

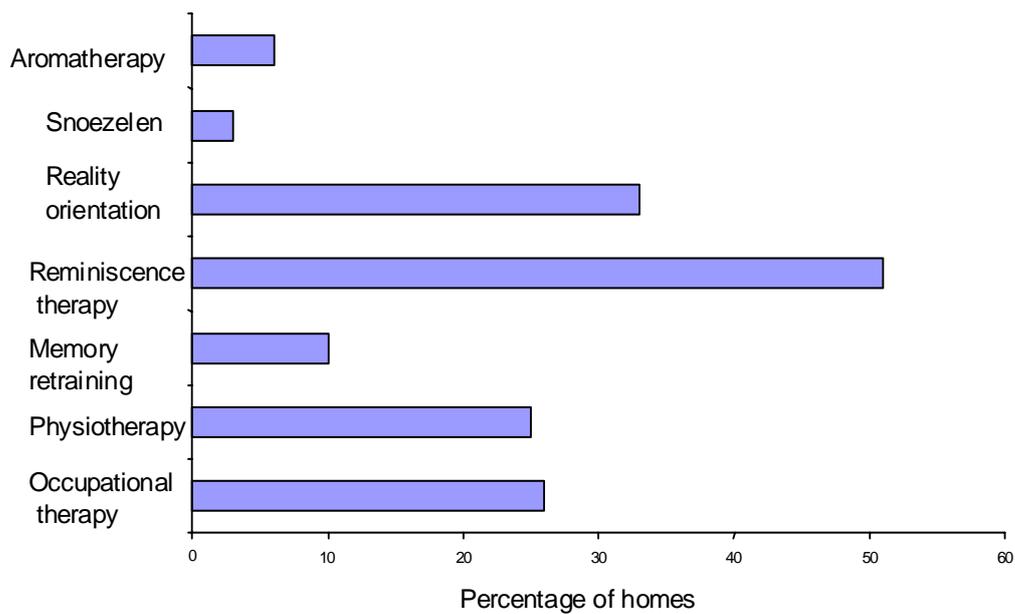


Figure 1: Percentage of homes offering specific therapies

Homes offered a variety of therapies to residents, with reminiscence therapy the most common, being reported by just over half the homes (see Figure 1). Reality orientation was offered in a third of homes, but approaches such as ‘Snoezelen’ (multi-sensory stimulation) and aromatherapy, which are suitable for more severely impaired residents, were reported in less than 5% of homes. About a quarter reported the availability of physiotherapy and occupational therapy.

“Our EMI residential unit focuses on maintaining and improving skills held by the person at the point of referral.”

The majority of homes offered residents regular outings (see Table 8) and 71% of the sample encouraged visiting from local groups. Similarly regular religious services were held in most of the homes. Provision of personal facilities including hairdressing services and beauty therapy was also generally good. A very few homes in the sample provided facilities such as support groups or befriending schemes for people with dementia and their carers.

SOCIAL FACILITIES OFFERED BY	PERCENTAGE OF HOMES IN
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HOMES	SAMPLE
Outings	89%
Visits from local groups	71%
Religious services	87%
Hairdressing	94%
Beauty therapy	46%
Escort to appointments	78%
Transport	54%
Support groups	9%
Befriending person with dementia	10%
Befriending carers of person with dementia	10%

Table 8: Social facilities offered by homes.

“Clients often like to go out – they are taken out regularly in the mini-bus just for a ride or to clubs, pubs, theatre, seaside, scenic drives, visiting friends and church or chapel if required.”

3.7: Referral to other services

Most homes (86%) reported referring residents on to other services. Table 9 lists the type of services to which referrals were made. Other referrals included Age Concern and the Huntingdon’s Disease Society. Most referrals were to Social Workers and to mental health teams / professionals. This suggests that the mental health problems of older people, including dementia, are seen as requiring more specialist input than the many physical health problems also encountered.

“Excellent input and access to the mental health team and social workers; GP also very supportive.”

“It would be beneficial if we had immediate access to mental health advice etc. where necessary to give an even better standard of care to our residents.”

TYPE OF REFERRAL	PERCENTAGE OF NURSING AND RESIDENTIAL HOMES
Neurology	25
Psychiatry	66
Geriatric medicine	58
Clinical Psychology	24
Physiotherapy	59
Occupational therapy	49
Speech and language therapy	51
Dietetics	59
Community Mental Health Team for Older People	51
Community psychiatric nurse	69
Social Worker	73
Memory clinic	10
Day hospital	37
Day centre	25
Home care provider	8
Alzheimer's Society	14

Table 9: Referrals to other services

3.8: Staffing

The homes were asked about the numbers and types of staff that worked in each home. These were referred to as 'part of service' in the questionnaire. Respondents were also asked about the numbers of staff not based in the homes but who they could have access to if and when required, for example a community psychiatric nurse who might visit the home to give advice on medication. Types of staff were grouped under several headings, including medical, nursing and care staff.

3.8.1 Medical Staffing

Table 10 shows the numbers and percentages of homes in the sample that have medical staff that either form part of the service or whom they have access to.

	HAVE ACCESS TO OR PART OF SERVICE
Psychiatrist – consultant	131 (56%)
Psychiatrist – other grade	113 (48%)
Geriatrician	29 (12%)
G.P.	194 (82%)
Neurologist	19 (8%)

Table 10: Numbers of homes (and percentages) reporting having medical staff as part of their service or having access to them

In only a few cases were medical staff described as ‘part of the service’; these included some homes where the proprietor was a medical doctor. It is perhaps surprising that only 82% of homes reported having access to a GP, as presumably every resident would normally be registered. This may reflect the difficulties some homes have in liaising with a large number of GP’s.

3.8.2: Nursing staff

The total number of qualified nurses who formed part of the service in the sample was 747 of which 158 were Registered Mental Health Nurses (RMNs). It is worth noting that the proportion of mental health nurses (21%) is much lower than the estimated prevalence of dementia (48%), perhaps reflecting the difficulty of recruiting nurses with this qualification. The total number of qualified staff that the homes reported having access to was 267 of which 53 were RMN’s and 178 were CPNs. Table 11 outlines the number (and percentage) of homes that had qualified nurses as part of their service and the number of homes that had access to qualified nurses.

	PART OF SERVICE	HAVE ACCESS TO
Qualified nurses	118 (50%)	68 (28%)
RMN’s	62 (26%)	35 (15%)

CPN's	3 (1%)	86 (37%)
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Table 11: Number of homes (and percentages) reporting having qualified nurses as part of their service, or having access to them

The proportion of homes reporting having qualified nurses as part of the service exceeds slightly the proportion of homes which are nursing or dual-registered homes (40%), suggesting a number of residential homes have qualified nurses as part of their service. About two-thirds of nursing or dual-registered homes report having at least one RMN as part of their service.

3.8.3: Other health staff

Table 12 shows information on the number of homes that employed other types of health personnel and the numbers of homes that had access to different types of health personnel.

	HAVE ACCESS TO OR PART OF SERVICE
Clinical psychologist	29 (12%)
Occupational therapist	43 (18%)
Physiotherapist	46 (20%)
Speech & language therapist	47 (20%)
Dietician	119 (51%)

Table 12: Number of homes (percentages) reporting having other types of health care staff as part of their service, or having access to them

In most cases, these professionals were accessed from outside the home, although a few Occupational Therapists and physiotherapists were employed as part of the service. In addition, 106 homes (45%) described having access to a qualified social worker, with 52 (22%) reporting access to an Approved Social Worker.

3.8.4: Care staff

There were a total of 4719 care staff distributed across the 235 homes in the sample. 51% were classified as health care assistants, 46% as residential care assistants, 2% as support workers and 1% as home care workers. The breakdown of care staff across homes is outlined in Table 13. The employment of home care workers is attributable to the outreach work undertaken by some homes.

“We are an EMI Home also providing day care, respite and care in the community.”

	PART OF SERVICE	HAVE ACCESS TO
Health care assistants/ Nursing assistants/ Nursing auxiliaries	108 (46%)	27 (11%)
Residential care assistants	108 (46%)	27 (11%)
Support workers	11 (5%)	15 (6%)
Home carers	6 (3%)	7 (3%)

Table 13: Numbers of homes (and percentages) employing / accessing types of care staff

3.8.5: Other staff

Homes employed or had access to a variety of other staff. 45% of homes had an activities worker as part of their service, with an additional 11% of homes reporting access to such a person. Nearly half of homes employed or had access to a Training Officer, and just under a third of homes reported employing / having access to a counsellor or advocacy worker. It would be of interest to explore further the roles undertaken by these latter groups of workers. A third of homes reported having a paid or volunteer driver, although the number of homes who reported having volunteer input generally was very low (11%).

3.9: Staff Training in NVQs

The numbers of staff currently employed who were trained to the various NVQ levels, together with the numbers of homes who employed staff qualified at this level is shown in Table 14.

“We try and provide all staff with NVQ training, but there are financial difficulties.”
(Home with 10/30 care assistants trained to NVQ levels 2 and 3)

	TOTAL NUMBERS OF STAFF IN SAMPLE	NUMBERS OF HOMES WITH AT LEAST 1 MEMBER OF STAFF TRAINED TO THIS LEVEL
NVQ Care – level 2	836 18%	189 80%
NVQ Care – level 3	269 6%	118 50%
NVQ Promoting Independence - Level 3	54 1%	15 6%

Table 14: NVQ trained staff

The numbers of staff in the sample currently undergoing training towards a qualification and the number of homes who have members of staff undergoing training to a specific level are shown in Table 15. In total, 25% of care staff were qualified at NVQ level 2 or above, and 22% of care staff were reported as undergoing training to NVQ level 2 or above.

	TOTAL NUMBERS OF	NUMBERS OF HOMES WITH AT LEAST 1 MEMBER OF
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	STAFF IN SAMPLE	STAFF IN TRAINING
NVQ Care – level 2	728 15%	175 74%
NVQ Care – level 3	272 6%	125 53%
NVQ Promoting Independence - Level 3	34 1%	13 6%

Table 15: Staff undergoing NVQ training

This indicates that at least 53% of the total sample of care staff have yet to embark on NVQ training. Three-quarters of nursing and residential care homes (182; 77%) reported that they had one or more accredited NVQ assessors working in the home. This represented 320 assessors, an average of 1.76 assessors per home having an assessor.

In Wales, the National Assembly's National Minimum Standards for Care Homes for Older People (2002) has set a target of a minimum ratio of 50% of care staff members (excluding registered nurses and home managers) trained to NVQ level 2 or equivalent by April 1st 2005. Figure 2 below shows the percentage of staff currently trained to NVQ level 2 or equivalent across homes. It is evident that the vast majority of homes in this sample currently have below 50% of staff trained to GNVQ level 2, and that many have considerable progress to make to meet this target. Only about 10% of homes currently meet the target, with over two-thirds having only 30% or less of their staff trained to this level.

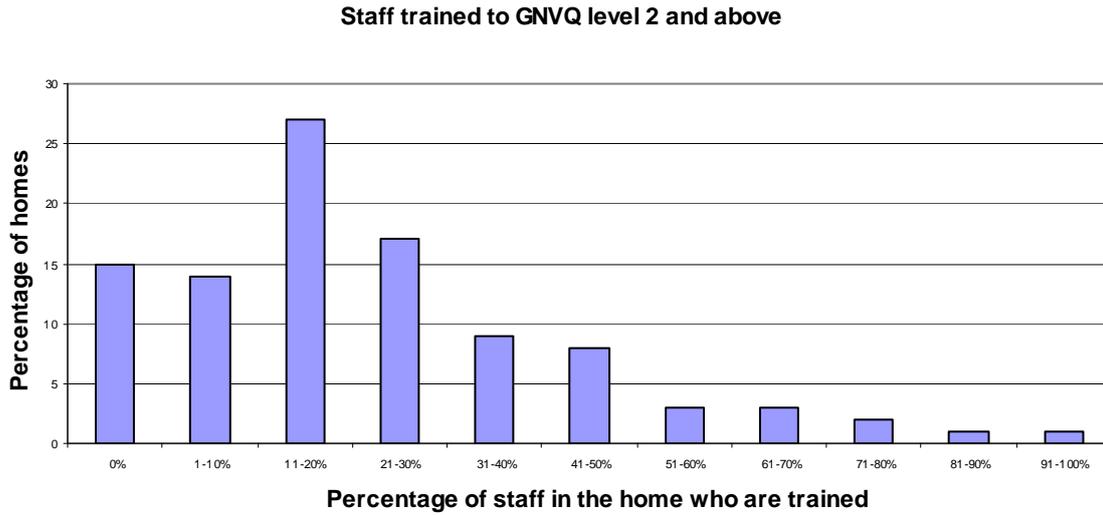


Figure 2: Proportion of staff in each home having NVQ level 2 or above

When those currently undergoing training are added in to the picture, the situation would then be as indicated in Figure 3.

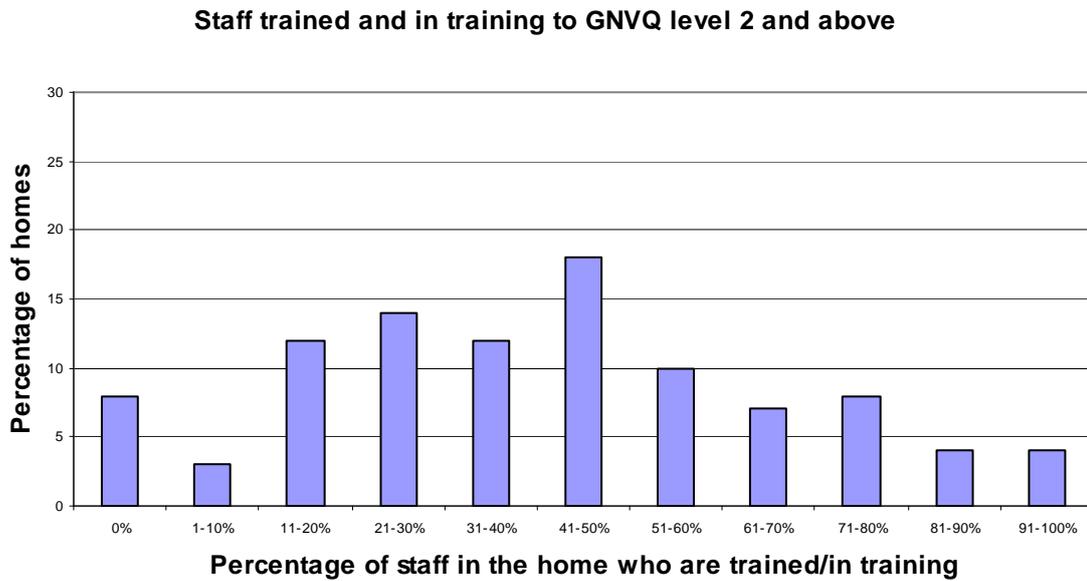


Figure 3: Proportion of staff in each home trained or in training to Level 2 NVQ and above

A third of homes would then meet the target, but over a third would still have less than 30% of the relevant staff complement trained to the required level, assuming all those currently training complete their qualification.

3.10: Staff training in dementia care

139 homes (59%) provided in-house training in dementia care, while 164 homes (70%) reported sending staff to other locations for training courses in dementia care.

“We encourage staff to train and widen our knowledge. We are proud of our Investors in People status.”

Courses in dementia care and their providers included;

- Working with people with dementia BASE & MIND
- Who cares Alzheimer’s Society
- Understanding Dementia Health Authority, Alzheimer’s Society
- SOLACE Cardiff & Vale NHS Trust
- Reality Orientation Social Services
- Mental Health in later life Age Concern
- Challenging behaviour DSDC Wales

“We have a member of staff undertaking the Diploma in Dementia Care at Leeds Met. University by distance learning. We would like to invest in Dementia Care Mapping training for staff, but can find nothing locally.”

“We offer Snoezelen, and all our staff have undergone a 1 day training course. All have also done a 1 day course in RO and a 1 day course in Reminiscence Therapy, organised by the local authority.”

“There are very few courses for carers in EMI Homes.”

75 homes (32%) had a member of staff who provided training in dementia care. They invariably provided training for employees in the home but also for other people based on site (in 9 homes) and people based elsewhere (in 12 homes).

In house courses included:

Dementia care

Dementia and Alzheimer’s, moving and handling

Abuse: Mental health issues

Challenging behaviour

Person centred care

Overall these findings are encouraging, in relation to the extent of training activity. However, there are 16 homes in the sample, which have residents with dementia but do not report any form of training in dementia care, and a number of others have extremely limited training (such as a 1 day course). Some homes mentioned difficulty with availability and funding of courses.

“Training has to be funded by staff themselves and can be quite expensive, so staff prioritise and don’t / can’t do all they would like.”

3.11: Language use

The *main* languages spoken by residents and staff in the sample were as follows

- English was spoken in all the homes
- Welsh was spoken in 69% of homes
- Sign Language was used in 6% of homes.

Just over half (54%) of the homes stated that one or more of their residents used Welsh as a preferred language. Of these, 8 homes did not have any Welsh speaking members of staff.

Nearly all (96%) of the homes stated that one or more of their residents used English as their preferred language.

“All residents speak Polish as a first language and most English as a second. Employ English, Welsh and Polish staff.” (Polish Home, North Wales)

“15 residents use Welsh as their preferred language and 50% of the staff are able to converse in Welsh.”

3.12: People with learning disabilities and dementia

73 homes (31%) reported being used at some point by people with a life long learning disability who had developed dementia. During the past year, 63 homes (27%) recorded that they had looked after a resident (totalling 108 residents) who had life long learning disabilities and dementia.

3.13: Younger people with dementia

Responses indicated that a total of 21 beds (0.3% of the total) were available *specifically* for younger people with dementia distributed across 8 homes. **However**, 42 beds (0.6% of the total) are *currently* in use by younger people with dementia across 22 homes. Over the past year, a total of 61 clients who were younger people with dementia had been cared for in 29 homes.

The Alzheimer's Society estimates that there are 893 younger people with dementia in Wales (2.19% of the total population of people with dementia). Younger people with dementia appear to be under-represented in this sample, constituting 1.4% of the reported 3032 people with dementia in the homes surveyed.

In total, just seventy homes (30%) stated that they could accept younger people with dementia.

“We do take residents under 65, but at present only have 2 residents just over 60. I feel it wouldn't be appropriate to have young people with dementia with our very old people, as interests and activities are quite different.”

“We have younger people with dementia in our day-centre, but because of registration, they cannot become residents.”

3.14: Support for families

74 nursing and residential homes (31%) reported providing carers support, with about half of these organising group meetings for families. 14 homes provide a newsletter for families

In light of recent findings that carers need ongoing support following admission of an older person to long term care, the provision of information and counselling for family caregivers is important and warrants further development. Carers commonly continue their caring role following admission of the older person to long term care

and often report a lack of a framework for negotiating their new roles and responsibilities within a care home setting. In addition provision of good quality written information has been highlighted as a key requirement by many carers (Seddon, Jones and Boyle 2001; Burton-Jones, 2001; Woods et al, 2000).

3.15: Research and Development

It was perhaps surprising to find that as many as 22 homes (9%) had a member of staff who was currently involved in conducting research. Findings were disseminated directly to colleagues (n = 18), within the organisation (n=15) on a Wales wide basis (n=3) on a UK wide basis (n=2) and internationally (n=1).

The 15 homes who were not in receipt of direct funding for the research saw research as a part of the staffs' role. 7 research projects were funded by the homes and 1 was government funded.

Ongoing or completed research projects included:

- Provision of day-care services
- Foot care
- Activities in Dementia
- Staff turnover in the workplace
- Dementia and Art
- Wound care
- Stroke care

4. Conclusions

This survey provides a snap-shot of residential care for people with dementia in Wales, immediately prior to major changes in registration arrangements and standards required. The situation is fluid, with many homes struggling to recruit and retain appropriate staff and questioning their economic viability under current funding regimes. Within residential care, it was clear from a number of responses that a great deal of valuable work is being undertaken, with a great deal of commitment, and at times creativity and flexibility. A number of clear areas for development emerge:

4.1: People with dementia are central to residential care

Nearly half of the residents in this sample were reported to have dementia. Only 7 homes reported having no people with dementia at all. Studies in England suggest that the actual prevalence of dementia will in fact be even higher, as many cases are unrecognised. Some cases are 'overlooked' or seen as 'confusion' in order to remain within registration requirements. It is clear that dementia care cannot be regarded as a specialist type of provision, but that *all* homes for older people need to make appropriate provision for the care of people with dementia. Some homes might usefully specialise in the care of people where challenging behaviour is more evident, but the presence or absence of dementia per se is not a helpful way of sub-dividing provision. All staff working in residential care with older people need awareness of dementia and skills in communicating with people with dementia and recognising and meeting their needs.

4.2: Training in dementia care

There are a number of training initiatives in dementia care, from half-day courses to degrees with a number of providers offering courses, including DSDC Wales. These courses are well-received, but need to be more available, and perhaps subsidised to ensure wider availability. Training in Dementia Care Mapping was one gap that was identified. The development of training packages, including CD-ROM's, would widen access and allow individual learning and development to be pursued. DSDC Wales has some experience in the development of such packages, and would be well placed to take this area forward.

Inevitably, the National Assembly's target of achieving 50% of care staff trained to NVQ level 2 by April 2005, will mean that most training energy and resource is directed towards this. This survey has shown that there is considerable work to be done in this respect, with some homes approaching the target, but many being a long way off. There is no specific NVQ in dementia care at present, so to meet the training needs of care staff who on a daily basis will be working with people with dementia, it is essential that dementia-specific materials and options are pursued in the training towards the NVQ and equivalent awards. The UK network of DSDC's is attempting to assist this endeavour on a UK basis, and DSDC Wales is participating in this.

In addition, there is a need to develop within Wales higher level courses, such as are being offered elsewhere in the UK, to allow practitioners in the field to develop their skills, knowledge, awareness and creativity, while remaining in practice. Such courses might be at Diploma or Masters' level, and incorporate an element of distance learning, together with the face-to-face contact and group learning, which assist greatly in broadening horizons and opening up new possibilities.

4.3 Input from specialist services

Dieticians and psychiatrists were the specialists most often reported as accessible by homes, although the majority of homes made referrals to CPN's and Social Workers also. Given the prevalence of dementia in homes, there is a case for more specialist input to be available, to perhaps prevent some of the crises that may lead to a psychiatrist being called in. CPN's and clinical psychologists may be available to advise on the management of challenging behaviour, for example, and assist staff in understanding the variety of factors leading to the problems they are experiencing, and encourage the development of a culture of care where such difficulties are less likely (e.g. Ballard et al., 2002). DSDC Wales (Bangor) is currently undertaking (with sister centres in London and Manchester) a Wellcome Trust funded project evaluating systematic assessment of needs of people with dementia in residential homes, with action plans implemented with the assistance of a trained nurse. This may provide a model for the input of specialist mental health services for older people to residential care. The currently limited evidence base in this area suggests that whilst training – as recommended in 'Losing Time' (Audit Commission, 2002, pp.33) – can be useful, it is ongoing advice and consultation on management of difficulties, and improvements to the care environment that make a difference to the quality of care and quality of life of people with dementia in residential care.

4.4: Younger people with dementia

The survey highlighted a dearth of provision for younger people with dementia. The relatively small numbers affected, makes the provision of services outside centres of population difficult, and there is a great need for creative ways of providing the care that is required by some of those affected. Younger people with dementia tend not to be seen as the remit of any particular planning group or provider; they may be tagged

on to older people's services, but also seen in neurology and adult mental health. In a future report, we will highlight the whole range of provision for this group; the provision in the residential sector is clearly inadequate, in terms of numbers and the mix with provision for much older people.

4.5: Involving families

Less than a third of homes reported providing support for relatives of residents. The frequent occurrence of on-going strain for family members of people with dementia after admission to residential care is well-established, and the Relatives & Residents Association has highlighted the need for, and benefits ensuing from, family involvement. This issue needs to be given more attention in residential care, and training materials, such as those developed by the Relatives & Residents Association and DSDC Wales ('Partners in Care'), made more widely available.

4.6: Activities and interventions for people with severe impairments

A variety of therapies are being offered to residents with dementia, with reminiscence therapy the most frequently reported. There is scope for more use of stimulation approaches, including music, aromatherapy and multi-sensory stimulation, which may be used where the person is too impaired to take part in reminiscence work (Woods, 2002). This issue also has training implications, so that staff are adequately equipped to carry out this work sensitively and effectively.

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6. Project Team

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Many thanks to all those in services in Wales who have responded to our questions patiently and courteously.

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