A Preliminary Analysis of Dementia in Wales
A report following a preliminary review of dementia in Wales

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Introduction

In 2009 a project brief was drawn up for a preliminary analysis relating to the current knowledge about and provision for people with dementia in Wales. The brief was to undertake some initial fact finding from people with dementia, their carers, some expert professionals and from desk top research to inform a possible wider review of dementia services at a future date.

After some consideration of various complimentary work being undertaken by the CSSIW it was decided that the content of the report should be reframed and primarily used to inform the second stage of the review of the NSF of older people. This piece of work will include the perspectives of people with dementia and will also look at commissioning as a potential future work stream.

Instead of following the sequence of items identified in the initial project brief this report begins with information gained from people with dementia and their carers. It then moves on to utilise the other information gained during the preliminary analysis and uses all this information to look at potential implications for the NSF review and commissioning which had been identified as a key area for a dementia focused review.

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1 See appendix 1 for the project brief details
Summary

The Welsh Assembly Government has recognised that because of the predicted 31 per cent increase in the numbers of people with dementia in Wales by 2021 there is a pressing need to review the provision and development of services for people with dementia – including social care and social services. *Fulfilled Lives, Supportive Communities* stated that ‘there are particular pressures emerging in dementia care (para 2.26) and the report *Reviewing Social Services in Wales 1998-2008* lists ‘providing good options for people with dementia’ as one of the 10 weakest areas identified in Joint Reviews. There is a crucial need to address this identified weakness.

A significant finding of the preliminary analysis is that there are wide variations in what is available across Wales and that this variability doesn’t seem to be related to need. Crucial gaps have also been identified. This means that the needs of people with dementia and their families and carers are not being adequately or equitably met by social care and social services.

People with dementia and their carers said that what they want and need includes access to flexible and responsive services which can meet their changing needs resulting from the impact of living with dementia over time. People described the problems they currently experience with being ‘picked up and put down’ by different agencies and want more integrated services that meet their practical, social and psychological needs. They are very aware of the differences in what is available across Wales and are unhappy about this. While some individuals had found and were using ‘good options’, for many people their choices were limited to what was available locally.

One of the keys to generating ‘good options’ is commissioning. To be effective commissioning needs to include the collation of relevant factual demographic information on prevalence and trends relating to dementia, but it must also include the views of people with dementia and their carers on what’s needed and what works well. This preliminary analysis suggest that further work is needed on each of these components and offers some suggestions about ways to do this.
1. The views of people with dementia and their carers

This aspect of the preliminary analysis was undertaken by taking part in specially organised meetings with people with dementia and their carers sometimes accompanied by professional staff.

Three meetings were held. Only carers attended one meeting organised by Cross Roads in south Wales while the other two were both organised by local Alzheimer’s Society groups. The south Wales meeting included people from Newport, the north Wales meeting included people from across Flintshire, Denbighshire and Conwy. In these latter two meetings carers were in the majority (and were mainly women) and the people with dementia were often recently diagnosed. Services used and discussed were therefore those more appropriate at the early stages of dementia such as day centres and respite rather than permanent residential care.

What’s people’s experience and what do they think is important?

The sessions were structured around the idea of a dementia journey and people’s experience of this, what had worked well and what was difficult as well as what needed improving.

Recurring themes identified from the meetings

People with dementia are individuals with individual needs, likes and dislikes. Their uniqueness must be understood and respected.

Beginnings are often difficult in terms of understanding what's happening, what to do and where to go next.

- GP’s: GP’s are critically important as they are often the first point of contact when problems appear.

People had very different experiences of GP’s some of whom were very helpful and others weren’t, but were often felt not to know enough about dementia. Issues around the way GP’s identified and ‘named’ the problems were raised. GP’s were important for starting people on the first stages of the dementia journey as they typically made the referral to a memory clinic. There were few comments about GP’s role later on in the dementia journey.

- Other health services such as hospitals were spoken of as ranging from appalling to brilliant. Most people seem to have been in contact with a memory clinic which had been a largely positive experience in helping people get both information and a link to other resources.

2 Further information about attendance is listed in appendix 3.
Example
A memory clinic based in a north Wales hospital holds a series of 6 sessions for people who have been newly diagnosed to explain what dementia is, sources of help etc. People were very positive about what they had gained from these sessions.

Getting and using information/signposting

β Signposting - memory clinics were valued for pointing people in the direction of information as well as expertise. Carers spoke of how the memory clinic linked them to a liaison nurse/CPN who then pointed them in the direction of support and services e.g. Cross Roads. ‘It was the button that got things rolling’.

β Once isn’t enough - understanding and applying the information about what was happening and what was available was really difficult for some people – the term ‘steep learning curve’ was used more than once. This meant that information sometimes needed to be repeated/ reframed/reinforced.

β The need for a single point of contact - people emphasised that there is a need for further information as the illness progresses; having a single point of contact for a carer and/or the person with dementia both initially and later on was rated as very important in simplifying what can be a difficult and potentially stressful process of ‘hunt the information’.

Examples:
The source of the single point of contact varied – for one person it was a CPN, for another it was the Admiral nurse ‘she is my crutch’, for others it was the support worker attached to the local Alzheimer’s Society and for another it was the special EMI service from a central office provided by Cross Roads which provides information, individual counselling, an ‘ear’ and advice, will advocate, groups etc.

The availability of this link person/contact when things are difficult – such as the carer’s moments of stress and frustration – were particularly valued e.g. being able to telephone and speak to a known person including in the evenings.

One woman spoke of how when she went to the memory clinic with her mother they did tests and told her – the daughter – that her mother was unchanged – while her experience of her mother was different from this. Cross Roads, because they knew both the carer and the mother said that they would liaise/advocate.
Feelings

People spoke movingly of how they experienced feeling heart broken, being unable to sleep, crying, living with the anxiety of not knowing what was coming next. They spoke of the stigma associated with the diagnosis – including from GP’s. Carers spoke of how they put on an act so as not to show the cared for person how they are feeling, especially as the illness develops. Loneliness, which is compounded by the gradual disappearance of friends, was an issue for those people who were further on the ‘journey’. More than one person spoke of how dementia had pulled the family apart.

While some people spoke of ‘trying to live as best you can’ and the need to be as normal as possible’ and ‘enjoy what you can now’ others spoke of frustration and sadness of how you ‘try to stop it progressing but you can’t’.

Acknowledging this shifting mix of focusing on the present as well as worrying about the uncertain future is essential to effective support services.

Hurdles

Carers described the hurdles they felt that they had to negotiate - not just in getting information, but in getting services, understanding benefits, taking on additional responsibilities, getting family members to understand what was happening and so on.

Lack of continuity – a significant part of the experience of there being endless hurdles to surmount came from the experience of discontinuity, such as between different day centres that a person went to, social workers closing your ‘case’, a lack of coherence in what is being provided. When there was continuity both the person with dementia and the carer benefited.

Example:
One carer spoke of how her husband attended a day centre run by Cross Roads – he was often reluctant to go, but the fact that some of the carers there also provided support to him in his own home meant that they knew him and he them so they were able to encourage him to go. The carer felt confident in his care and happiness because of the continuity.

People said that overcoming hurdles requires stamina and what’s provided must help sustain carers as well.

Day centres and lunch clubs

These seemed to be a valued support for carers both in terms of the ‘space’ it provided for them but also for what it offered the person with dementia.

Atmosphere and activities - people with dementia liked them if they had an informal friendly atmosphere, they were listened to and accepted. ‘I
felt as if I had been invited’. They felt that being able to reminisce was very important for self esteem as was discussion of personal interests. One man spoke very emotionally about how he felt that he had not been treated respectfully and a number of people commented on how institutionalised day centres can be. The right attitudes and training of day centre staff were seen to be very important.

Cross Roads run a group for men which includes more traditionally familiar activities for men.

Access to day centres – longer and more flexible opening times are appreciated, for example the Cross Roads centre opens until 5.30 pm for 364 days a year.

People told of how the opportunity to go to a centre seems to stop when dementia is more advanced (or if people are no longer mobile) putting more pressure on the carer. One carer spoke of how since this had happened she felt that both she and her husband are limited to their own home 24/7. ‘You either cope at home or it’s residential care – there’s no other choice’. ‘I feel that I’m neglecting him and I would like to get him out into the fresh air’.

BUT – not everyone liked day centres and these appear to be one of the main provisions for people in the early stages of dementia. For people who don’t like centres or for people in more rural and isolated communities other opportunities need to be available.

Informal supports

These got the biggest thumbs up, especially the Alzheimer’s groups themselves and those provided by the specialist Cross Roads service. There is a ‘drop in’ centre in north Wales – two hours per week - which is just for people with dementia and one person said ‘it’s so nice to be with people who are as daft as me.’

The importance, support, morale boosting and comfort of being with other people who understood about dementia was stressed.

Other semi- formal supports such as a special singing group/ dementia choir were appreciated and there is increasing research evidence of the positive benefits to be gained from attending such activities.

Examples

A bequest had been left to the local Alzheimer’s society after a woman had had a refund from continuing care funding. The money was used for a holiday to Torquay for 32 people – people spoke warmly of the mix of something different from the everyday, being with people who understood and the fun that this unexpected holiday provided. Day trips were also loved for the same reasons.
A ‘dementia café’ provided by the Alzheimer’s Society meets monthly and offers tai chi, painting and dancing as well as refreshments. Forty seven people went to the Newport café the previous month.

### Tools and others resources

People are eager for ‘easy to use’ and effective techniques and tools for use by carers or with the person with dementia

**Examples:**

One carer spoke of how he had developed a simple laminated sheet on which he provided information about his mother and her likes/dislikes which he took with him when she went to unfamiliar places such as for an appointment, to a day centre or into respite – this included the facts that she always wore her watch on the outside of her cuff and she liked her shoe laces tied tightly.

A more ‘sophisticated’ version of the laminated sheet has been developed by Cross Roads. This is called a Life Journey Album into which items which can support and trigger memories can be placed – e.g. photos, post cards, material etc. It can be bought for a small charge.

More specialist housing and assisted living to allow couples to stay together were wanted. One person had recently moved with her husband into extra care housing where there were seven specialist rented flats with meals on site, an enclosed garden. She was thrilled that he was eating better and less agitated – evidence that positive progress is possible with the right supports.

### Professional supports

**Social work:** people wanted access to social workers and to social work support.

From the accounts provided it seemed that social workers were often part of the ‘picking up and putting down’ phenomena and that they tend to figure more at later stages of the illness. People spoke of how social workers left their telephone numbers and the suggestion that the carer should make contact if necessary. While some people felt that this was appropriate others felt that it meant that ‘it’s up to you’, ‘they leave you high and dry’. One person had had 4 different social workers – she bemoaned the fact that ‘you have to start again each time’.

Rules about eligibility for services based on age can also break the continuity of social work supports – thus the specialist senior social worker for younger people with dementia described how she could no longer provide support to one carer now that her husband was over 65 years old.

One person spoke positively of the support provided by a social work student as it was more intensive however, she hadn’t been replaced when she left. The specialist senior social worker also spoke of the importance of providing
practice learning to social work students who could provide more time to service users and their families.

There was limited experience of carers’ assessments. What was wanted were assessments which were clear and actionable.

Health professional such as CPN, liaison nurses were valued for the expertise and information they provided. Admiral nurses are dementia specialist nurses and can provide help with techniques such as distraction, stress management.

**What people said that they wanted as core services/supports**

Each group was asked what they wanted ideally – the amalgamated lists below therefore are spontaneous responses and aren’t weighted in terms of being essential or desirable.

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<th>Core services /supports wanted</th>
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<td>• Pro-active not reactive professionals.</td>
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<td>• Admiral nurses.</td>
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<td>• Specialist social workers for both older and younger people with dementia – so there is continuity of worker.</td>
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<td>• Good CPN.</td>
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<td>• Nurses on general wards to have training in dementia.</td>
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<td>• GP’s to do home visits when the person with dementia refuses to go to the surgery.</td>
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<td>• 24 hour call line – someone to talk to when stressed.</td>
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<td>• Cover for emergencies.</td>
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<td>• Ways of educating the wider family about dementia and effect on person and carer.</td>
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<td>• Post diagnostic groups and clinics where there is information about what’s available, providing training to carers and support group.</td>
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<td>• Specialist respite for younger people with dementia.</td>
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<td>• Regular respite which can be booked in advance – currently respite is often only when it’s available not when you need it.</td>
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<td>• Drop in centre where can go for advice and support – could be on a specific day and time.</td>
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<td>• Day centre 10am – 4pm Monday to Friday with free transport and lunch or open for a longer day.</td>
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<td>• Saturday centre.</td>
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<td>• Stimulating activities to do at centres so achieve something, mental stimulation – not just marking time.</td>
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<td>• Support workers who are able to work 1:1 and help with interests and hobbies of the person with dementia e.g. gardening, football interests.</td>
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<td>• Carers grants for e.g. gardening and decorating.</td>
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• More singing group – there is one funded by the Alzheimer’s Society called Flintshire Sounds.
• More assistive technology.

2. Information about the pattern of provision of social service and social care

The initial brief for the preliminary analysis required the collection of information about existing provision of social services and social care. Since it was a small scale study rather than attempting to compile a complete picture different approaches to gathering and analysing information were identified. Problems with gathering and interpreting information about provision as well as gaps were also identified. Each of these has implications for commissioning.

What’s known about prevalence and provision?

What’s already known

The desk top research and meetings confirmed that there is a wealth of information about the prevalence of dementia against which information about provision needs to be set. It is available in differing degrees of focus, currency and comparability; for example

- in ‘broad brush form’ as can be found, for example, in the new handbook for CSSIW inspectors and in the Twining report. Some examples of these prevalence figures are provided in appendix 4.

- updated demographic information – as in the article in the Guardian newspaper on 21 September 2009 which highlights the global impact of the increasing numbers of people with dementia and the impact on carers. Information such as this provides an important context for the NSF review.

- local and regional information about prevalence and provision in Wales. The Dementia Services Development Centre (DSDC) confirmed that in their experience local information both factual and anecdotal is likely to be available. For example, there is a wealth of information that can be collected from local authorities and health boards about the provision of regulated services and probably of many unregulated services as well. Some localities are already trying to collect this information in a systematic way.

Example

The new NHS Board for North Wales has set up a sub group for ‘Older People and Mental Health’ which has obtained information from each local authority within the locality using a template to collect the figures. It is thought that this information will be used to make regional comparisons as well as inform future planning.
- regulated services - CSSIW regions and regulation inspectors know about regulated services in their area/region and will be able to provide up to date figures on, for example, the number of places registered for people with dementia in care homes and care homes with nursing. These figures are likely to be close to 100 per cent accurate in terms of settings but may not be accurate in terms of the number of people with dementia actually living in care.

- non regulated provision - the Alzheimer’s Society, which provides a range of community based advice and supportive services, suggested that information about non regulated services may be seventy per cent accurate and certainly organisations such as theirs will be able to provide information on what they provide, the take up as well as plans for future developments.

- other sources of information about related and relevant provision include the housing directorate in WAG who could provide information about supported housing organisations e.g. RSL.

Problems with collecting information on provision

The preliminary analysis was told of a number of issues including

- Lack of a standardised Wales wide framework/template for the collection and analysis of information about the provision of social services and social care for people which makes comparison and assessing equity of access problematic.

- Possible undercounting
  - Social workers working in older people’s teams and those in some generic adult mental health teams may not distinguish statistically between those service users with dementia and others;
  - social workers might be predominantly working with people with dementia and their carers but not be identified or counted as specialist social workers;
  - at the point of admission a person going into residential or nursing care may not have a diagnosis of dementia but may be in the process of developing the illness;
  - more informal arrangements such as dementia café’s may not ‘count’ attendees with reference to whether or not they have been formally diagnosed as having dementia.

- Possible double counting
  - some money may be provided to support carers projects/services in general with that also being counted as provision to carers of people with dementia;
  - some people may be using a range of day care services in the same week – such as those provided by the local authority, some by health and some by the voluntary sector.
Movement between services
- carers spoke of how they and the person with dementia they care for are “picked up and put down” by services – for example when the person is admitted to hospital they may be withdrawn from existing home care support and from an allocated community based social worker and re-allocated to a hospital based social worker and on discharge to short term home care/re-ablement. When these arrangements come to an end there may be a time lag before services are resumed – this seemed to be particularly the case in relation to social work support.

Short term funding

At one meeting I was informed that a much valued service – that of an Admiral nurse – was due to cease at the end of 2009 when funding ran out. The nurse appeared to be the only one in Wales although the service is more established in England. It is health funded.

Professor Bob Woods of the DSDC also emphasised that, taken together, the difficulties with collecting and comparing provision except in a provisional way means that it is difficult to estimate the ‘spend’ on dementia related provision.

Ideas for gaining information about provision

Further work is therefore needed to establish a more accurate and comprehensive picture of provision and to link this to the development of commissioning and funding for dementia related services.

Ways that this might be done include

1. Evidence from existing commissioning plans for people with dementia and the information collected to inform it.

2. Evidence from initiatives/research to collect and collate information about services for people with dementia and their carers, the date when this was undertaken, the results and the use of the results.

3. Information on regulated services including
   a) Twenty four hour provision
      - residential care places that are available for people with dementia
      - nursing homes places that are available for people with dementia
      - any places that are designated for younger people with dementia.

   b) home care provision of specialist/focused services for people with dementia
      - in house
      - private/voluntary sector providers.

   c) social work support
      - numbers of specialist social workers for dementia care
      - numbers of older people’s mental health social workers.
d) joint/shared provision with the local health providers.

4. Information on non regulated supports and activities including
   - support to carers/carers groups including training, support groups etc
   - day time supports including day centres, drop in centres such as café’s with information on places available, hours and days of opening, waiting lists provided by local authority, health, private and voluntary sector such as Cross Roads, Age Concern, local Alzheimer’s Society

5. Information on specialist housing provision.

6. Information on how ‘hidden populations’ are sought/identified

Example
A senior social worker in Flintshire undertook research including figures relating to callers to the duty system in order to find younger people with dementia. Although over 40 people were identified she believes that there are other younger people who aren’t currently known to social services.

7. Examples of innovative projects

**Gaps and insufficient provision**

Professor Bob Woods of the DSDC spoke of the following gaps that the centre had identified:

- preventative support - social care tends to come into effect only when dementia has become severe;
- low level interventions - e.g. befriender and buddying schemes as well as drop in cafes;
- more incentives for rehabilitation - at the moment people go into residential care, often from hospital, and rarely come out .. need more possibility of ‘changing the direction of travel’;
- more work on palliative care and dementia;
- role of direct payments and personalisation – how can it be dementia proofed?
- funding and commissioning needs to be more collaborative.
Quality of provision/good practice examples

The preliminary analysis was asked to seek out examples of good practice. This proved difficult as is shown by the information provided in the next paragraph.

Significantly people with dementia and their carers emphasised that quality as well as spread of provision is crucial - especially if a scarcity of provision affects their choice of services. This seemed to be true in relation to day centres, respite and residential care.

Finding examples of good practice

a) The DSDC said that they didn’t collect examples of good practice systematically, rather they heard about them more serendipitously – mainly about things happening in North Wales.

Professor Woods stated that good practice tended to be ‘individual led’ e.g. related to a specific manager of a residential setting, but examples of initiatives for younger people with dementia tended to stand out as this is starting from a low base.

Examples from the DSDC

- ‘Engage’ got funding for 6 projects in N Wales of which 2 may be for people with dementia.
- Gwynedd had an artist in residence working with people with dementia.
- Alzheimer’s Society reminiscence project did ‘art’ at a meeting.
- The Journal of Dementia Care carries many examples.
- R. Rowett’s directory developed for the Care Council for Wales.
- ACE club in Rhyl run by a proprietor of a residential home.
- Eden model of residential care for people with dementia.
- Dementia café’s.

b) The Alzheimer’s Society do not have a directory of good practice as it is hard to keep this up to date and comprehensive.

c) The Care Council for Wales has funded the compilation of a directory and some research on the use of tools in residential care.

d) SCIE have opened a dementia portal.
3. Consideration of relevant national and local studies and research

In the preliminary analysis a range of documents were read in whole or part as listed in appendix 1. Of these the most significant for their implications for a focused review on planning and commissioning were

The Twining Report
The Dementia Action Plan (draft)
The 2009 draft Commissioning Guidance and Good Practice Guide
The review of the NSF for older people

Question – what do the studies tell us that is useful for the work of the NSF review?

What follows is a brief summary of some key aspects of these documents followed by charts which link to possible review questions and analysis.

The Twining report

Dr Twining argues that there is no lack of strategy, rather there are a number that relate directly to people with dementia. What is important is to move beyond these strategies to robust implementation in an interconnected way using the best approaches from within and outside Wales.

His report looks at existing strategies including the NSF for older people, the broader strategy for older people, Making the Connections, Fulfilled Lives, Supportive Communities, the mental health NSF, carers strategy, housing and assistive technology and so on. The report also looks at the care and health standards and annual inspection reports as well as some research. Each of these is used to generate questions related to the implications for people with dementia and the responses needed.

Dr Twining concludes that people with dementia are people first; that planning for dementia is everybody’s business and that by getting things right for people with dementia we will be getting things right more widely and is thus a solution to developing better services in Wales, not simply an increasing burden.
# Key messages from the Twining Report

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<th>Message</th>
<th>Possible areas for consideration/analysis by the NSF</th>
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<td>There is no shortage of strategy — or recommendations - what is needed is robust implementation in an interconnected way with continuing oversight to support implementation</td>
<td>Evidence of joint work with key colleagues and agencies in planning and commissioning accompanied by evaluative arrangements</td>
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<td>Many of the existing strategies and NSF need to be read and considered in relation to people with dementia including - the NSF for older people, - the strategy for older people, - the NSF for adult mental health - the carer’s strategy - Accommodation for Older People in Wales (2007) housing and assistive technology</td>
<td>Ask LA and their partners in what ways these different strategies are integrated into commissioning plans and delivery</td>
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<td>Implementation should use the best approaches from within and outside Wales</td>
<td>Evidence of knowledge of and use or research findings on ‘what works’ Feedback from people with dementia and their representatives</td>
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<td>How far do current commissioning arrangements help or hinder progress in relation to dementia?</td>
<td>E.g. what is the mix of low and high intensity supports, innovation and more of the same? How far are there constructive arrangements for involving the third sector as well as the independent sector in developing and providing both regional and local services in a coherent way?</td>
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<td>Predicted increase in numbers needs to be refined to account for key variables which influence the type and magnitude of support required – including e.g. younger people and people with learning disabilities who have dementia</td>
<td>Evidence of data analysis being used to inform planning and commissioning via - collecting, collating and analysing current figures and trends relating to people with dementia and their changing needs - identification of key variables that influence the type and magnitude of supports needed What evidence is there of cross authority commissioning and services to ensure that the needs of smaller groups of people with dementia e.g people with learning disabilities are met?</td>
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Dementia affects life expectancy – but end of life (EOL) care issues for people with dementia not always considered

EOL care pathways to be considered in relation to planning as well as delivery of services

‘Dementia proofing’ is needed to ensure that all policies and initiatives are dementia friendly

Is this happening and if so how?

Workforce skills and deployment are crucial

What are the links between planning, commissioning, contracts and working with providers to ensure that the workforce capacity and competence meets the aspirations of and outcomes wanted by planners and people with dementia? How is quality service sustained?

**The draft Dementia Action Plan**

In October 2008 the Minister for Health and Social Services, Edwina Hart AM established a Task and Finish Group to develop a dementia action plan. The draft was made available for consultation in April 2009 and comments were to be received by mid September 2009. At the time of writing this report the results of the consultation are being considered.

**The draft Fulfilled Lives Supportive Communities Commissioning Framework 2009**

This framework was open to consultation until October 2009 and the results of the consultation are being considered and therefore some of the information provided in this section may be modified in the final framework.

The draft defined the purpose and scope of commissioning in terms of both fulfilling statutory responsibilities and shaping services to meet the social care needs of people both now and in the future. Part 1 included 13 standards which LA are expected to achieve. They ‘centre on evidence based commissioning plans and their delivery through effective procurement’. Part 2 included 9 key challenges that face commissioners and proposes a model of commissioning that places the citizen at the centre of commissioning activity.
### Key aspects of the draft commissioning framework

<table>
<thead>
<tr>
<th>Standards</th>
<th>Possible areas for consideration/analysis by the NSF</th>
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<tbody>
<tr>
<td>13 standards are set to assist the achievement of effectiveness and sound governance</td>
<td>The standards could be adapted to underpin the methodology for key areas to be explored and for interview schedules. Each could be made ‘dementia specific’, e.g.</td>
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<tr>
<td><strong>Standard 1</strong> requires specific plans for particular population groups – these could be for e.g. young people with dementia</td>
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<tr>
<td><strong>Standard 2</strong> requires sound evidence base and research to inform commissioning plans</td>
<td></td>
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<tr>
<td><strong>Standard 3</strong> requires commissioning plans to develop models of service delivery that minimise escalation of care needs and adapt to changing needs</td>
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<tr>
<td><strong>Standard 4</strong> requires citizen involvement including providers</td>
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<tr>
<td><strong>Standard 6</strong> emphasises the needs for flexible responsive services while</td>
<td></td>
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<tr>
<td><strong>Standard 7</strong> emphasises continuity of care</td>
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<tr>
<td>9 challenges are identified which include shifting to an outcome focus, designing services using a whole system approach, putting citizens at the centre, making joint commissioning a productive process.</td>
<td>These challenges could be used as a framework for asking for examples of good/innovative practice</td>
</tr>
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### Phase two of the review of the NSF for older people

The NSF sets national evidence based standards for the health and social care of older people in Wales and sits within the framework of the strategy for older people.

The initial phase of the review was undertaken in 2008 and looked at a number of cross cutting themes (dignity, nutrition and integrated services) in order to answer the question – what impact is the NSF having on the quality of life of older people in Wales? Findings were produced which evidenced both progress and areas for development.
The second phase began in the summer of 2009. In this phase the NSF standards will be looked through the ‘lens’ of particular groups of older people including some who have dementia. The fieldwork for the five concurrent work streams will take place between October and April 2010. It is envisaged that the SSIA will consider the review from a commissioning and planning perspective and will review issues such as how are integrated services working, how are services developed, what are the barriers to progress.
Conclusions

- People with dementia and their carers have detailed and informed views of what it is to live with dementia and what supports they appreciate and need. Their views and information should be embedded in further work undertaken on addressing the issues raised by dementia in Wales in the 21st century.

- The evidence from this preliminary analysis supports both research and anecdotal evidence of the patchy planning and service response currently available to people with dementia and their carers and the need to address this comprehensively and urgently.

- Good options need to include a focus on enrichment not a deficit approach to understanding and planning for dementia including for the more hidden populations of people affected by dementia.

- A focus on innovative projects as well as more standardised responses could be used to evaluate what works over time.

- The preliminary analysis undertaken by the project should be used to inform the ongoing work of the second stage of the NSF review.

- The final Dementia Action Plan and the Commissioning framework need to be integrated into any further work plans for the CSSIW on dementia provision and quality.

- There is a need to disseminate information on ‘what works’ so that effectiveness can be combined both strategically and operationally with the effort expended on responses to dementia.
Appendix 1 The project for the preliminary analysis

**The purpose of the preliminary analysis** was described as

To produce a preliminary analysis which establishes the scope of and methodology for, a focused review and to identify relevant data.

The analysis should set out

- The proposed scope of a focused review;
- The methodologies to be used;
- The outline of current information available;
- An overview of the issues and areas for further consideration for the focused review.

**Scope**

Areas to be considered in this stage to include

1. Information about the pattern of provision of social services and social care services to people in Wales with dementia, including services both regulated and unregulated.

2. Consideration of relevant national and local studies and research eg Scoping review, Dr C Twining (2008) and “See me, not just the dementia” CSCI June 2008.

3. Links to the emerging findings from current work being undertaken by the national dementia planning group.

4. Links to the current review of the National Service Framework (NSF) review for older people.

5. The views of stakeholders both internally and externally about the key issues and questions relevant to the full review.

6. Identify examples of good practice where appropriate.

**Product**

A report with findings, conclusions and recommendations about how to move the review forward, taking into consideration the read across the NSF if appropriate.
Appendix 2 Sources used to inform the report

Alzheimer’s Society publications including
- Dementia UK 2007
- Home from Home 2007

- briefing papers on e.g. neuroleptics/anti-psychotic drugs

Care Council for Wales including
- workforce action plan
- draft dementia directory compiled by Roger Rowett and partners
- report on project by Roger Rowett
- knowledge and skill sets re dementia care and for end of life care

CSSIW supplementary guidance on inspecting services for people with dementia 2003

CSSIW 6/2009 Impact of the NSF for older people in Wales Phase I initial findings and themes

CSSIW Older people with dementia - Handbook for CSSIW inspectors on implementing regulations and national minimum standards in care homes 2009


Dept of Health:  Dementia Strategy for England – living well with dementia

Dr Charles Twining, Dementia Strategy in Wales – a brief scoping report 2008

NICE; Clinical guidance on supporting people with dementia and their carers in health and social care (2006)

WAG:

- Strategy for Older People in Wales 2003
- NSF for Older people in Wales 2006
- Fulfilled Lives, Supportive Communities: A strategy for social services for Wales over the next decade 2007
- draft National Dementia Action Plan for Wales (June 2009)
Supplementary reading
Brooker Dawn, 2007 *Person centred dementia care* Jessica Kingsley

Davis Basting Anne, 2009 *Forget memory – creating better lives for people with dementia* John Hopkins University

Downs M and Bowers B (eds), 2008 *Excellence in Dementia Care*. McGraw Hill/OUP

James Oliver, 2008 *Contented Dementia*. Vermillion

Stokes Graham, 2008 *And still the Music Plays - stories of people with dementia*. Hawker Publications
Appendix 3  Meetings held with service users, carers, professionals

1. Vale of Glamorgan Cross Roads group for carers of people with dementia, July 2009
   This was a specially arranged meeting and lasted about an hour and a half
   Attendees included
   - 6 carers
   - Scheme manager
   these carers completed forms showing what other support services they
   accessed – these included: lunch club, men’s group carers support group
   carers social group for carers and their loved ones, care and support at home,
   Cross Roads day centre, LA day centre, Morfa unit (NHS)

2. Alzheimer’s Society Group Newport for people with dementia and their carers, July 2009
   This was a specially arranged meeting and lasted about an hour and a half as
   the group had gone to the ‘wrong’ hotel for the meeting!
   Attendees included
   - 7 carers and 4 people with dementia
   - Newport Area Alzheimer’s Society support worker
   - PA to the Director who had organised the meeting and who took notes

3. North Wales Alzheimer’s Support Group, September 2009
   This was a regular quarterly meeting but my visit was the sole agenda item
   and lasted over 2 hours
   Attendees included
   - staff from the Alzheimer’s society – an area manager, 3 from Denbyshire
   and a support worker
   - senior social worker for younger people with dementia from Deeside,
   - an Admiral nurse
   - a community nurse
   - approximately 16 people who either had dementia or were carers (no names
   were taken) and who usually attended the quarterly group meeting for North
   Wales organised by the Alzheimer’s Society.


5. Ian Thomas Director of the Alzheimer’s Society Wales, June 2009

6. A telephone call was also held with Roger Rowett ‘to discuss the projects
   being undertaken for the Care Council of Wales
Appendix 4 Some figures relating to dementia and implications for provision

Prevalence of dementia, implications for service provision

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<tr>
<th>Increasing numbers</th>
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<tbody>
<tr>
<td>Many reports emphasise the growing numbers of people who are and will be affected by dementia – both directly and indirectly as carers.</td>
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</table>

There are currently 700,000 people with dementia in the UK of which there are about 35,000 over 65 in Wales. By 2021 it is estimated that the numbers of people with dementia across Wales will have increased by 31 per cent to approximately 48,000 with people over 75 making up 85 per cent of the increase (Alzheimer’s Society 2008). This is a substantial forecast increase over the next ten year period.

The draft Dementia Action Plan (2009) identified increasing differences across rural and more urban areas of Wales, with some rural areas facing a proportionately greater increase – thus posing particular challenges for commissioning and provision of services.

It is estimated that half to three quarters of carers have significant psychological illness while up to a third have clinical depression (Guardian 21 September 2009).

<table>
<thead>
<tr>
<th>Changing patterns of demands on services</th>
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<tbody>
<tr>
<td>It is predicted that the increasing number of people with dementia will have an impact on existing services such as access to intermediate care, community based mental health teams, specialist home care and housing provision.</td>
</tr>
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</table>

While some new community service responses are developing - such as telecare and assistive technology – it appears that people with dementia and their carers are often having to fit into the existing patterns of provision such as day centres; with insufficient access to innovative projects.

It is estimated that 2/3rd of people in residential care have dementia, placing significant demands on the skills as well as the availability of the workforce.

<table>
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<tr>
<th>Shortfalls</th>
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<tr>
<td>Recent research suggests that Wales may be particularly poorly placed in relation to residential and nursing home provision.⁴</td>
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</tbody>
</table>

⁴ Research by Laing and Buisson reported in March 2009 which found that Wales has 14 residential and nursing home places per 1000 population aged over 75 and over, this is fewer than anywhere else in UK. Dedicated dementia capacity was the 2nd lowest across the UK with 9 per 1000. However these figures need to be set against the provision and take up of supports to people to continue living in their own homes.
Sixty two per cent of care home residents are currently estimated to have dementia but less than twenty eight per cent of care homes are registered to provide specialist dementia care.

The DSDC emphasised that there was also a short fall of low level responses particularly from social services.

**Specific groups/range**

Younger people with dementia - it is estimated that there are approximately 730 younger people with dementia and it is clear from discussions with the Alzheimer’s Society and the DSDC that there are very limited services available for younger people with dementia across Wales. There are 198 registered places for younger people with dementia in care homes. I was told that there is some discussion in the independent sector in north Wales of establishing some residential options for younger people.

Younger carers - services to carers are mainly aimed at older people, as they are the majority of carers. The needs of younger carers may not be being assessed and provided for. The Admiral nurse told of one ten year old boy she was supporting who was acting as a carer to his grandmother who has dementia.

People from black and minority ethnic communities
I have not been able to hear about or collect any information about specific responses and services for BME - the DSCD mentioned the Polish community in N Wales when asked.

People with learning disabilities
People with Down’s syndrome are statistically more likely than the general population to develop dementia. It is estimated that almost ten per cent of people of people with Down’s aged between 40 and 49 will have dementia, while this figure increases to just over 30 per cent for people between 50 and 59.

All of these pose particular challenges for commissioning in relation to smaller groups of people affected by dementia whose needs, supports and aspirations may well be different from those of older people.