

iris

Stimulating Thinking on dementia policy and practice from the
Dementia Services Development Centre at the University of Stirling

01. Thinking long-term: the future of dementia in the UK

A Positive Picture?

Dementia is now firmly established as a priority for action in the UK. At one level this is visible in high-profile policy commitments, announcements, and strategies and, for England and Wales at least, a Prime Ministerial Dementia Challenge. But dementia is also something which more people are increasingly, out of sheer necessity, facing up to as individuals, as members of families, as communities and as providers of services. This looks like being the decade in which dementia is finally coming of age. On the face of it we are all starting to get to grips with what dementia means for us individually, socially and economically. Opportunities seem to be opening up which could make a difference.

So this should be a good time to take stock of the way dementia is going in the UK. It would be difficult not to welcome a national drive to improve the experience of people with dementia, but the idea here is not to rehearse again the apocalyptic “scale of the challenge” or review the detail of policy direction and practice. The aim is to focus on the credibility, depth and impact of what is currently happening – the evidence, governance and ethics of national policies and local action. Are the right things being done? Does the current activity stand up to scrutiny? Are there any issues which should be picked up now which will improve long-term change?

The Right Focus?

On the face of it there appears to be a lot of action in all four countries at national level – programmes, initiatives, projects – supported by key professionals, public figures and dementia organisations. However it is clear that in fact little of the strategic intent and virtually none of the investment being trumpeted is new. The first question is whether the main difference between the approach to dementia taken over the last ten years and the focus in the last year is really just one of profile not substance. If so this has to raise concerns about whether the drive forward will actually deliver long-term, sustainable improvement in the lives of people with dementia.

The second question is perhaps more fundamental. Are evidence, and especially the detail of evidence of what works, being used sufficiently to drive national policies and the specific programmes which they are supporting? Where such evidence exists this should certainly form the centre of any serious attempt to make transformational difference. Maybe because of a need to secure a sense of momentum to meet certain deadlines, the focus does seem to be more on inputs than a rigorous assessment of likely at impact or long-term outcomes.

This report picks up issues raised at a Roundtable Discussion held at the Royal College of Nursing in London on 30 November 2012 and hosted by Professor June Andrews, Director of the Dementia Services Development Centre.

Written by
Professor June Andrews
Mark Butler

There is no excuse for this. Evidence clearly supports the value of a range of different high-impact interventions which the state and others can make where the collective outcome could be a step-change in the way dementia is experienced. These include widespread formal education for professionals and carers, 24/7 support to individuals in the community, increasing diagnosis, promoting exercise and stimulation, specific environmental adaptations and community support. There is much more. Some of this evidence has of course been used and is visible in the thinking but even amongst those endorsing the current approaches there is some private concern about the levels of rigour, transparency and accountability being displayed in what is happening.

Nor is there sufficient evidence of any serious attempt to address the damaging and inaccurate way in which dementia is framed in the media and the arts (and in some policy and professional thinking). This paints a picture of dementia as an unrelenting blight on individuals, families, communities and society with little hope and no joy. Those illustrated are often atypical; younger, more articulate, whiter and in an earlier phase of their illness than the majority of people with dementia. Challenging and re-framing the way people with dementia are portrayed matters hugely in the long-term.

There is a danger that the considerable noise generated by recognition of dementia as a social and economic priority has drowned out real engagement with the evidence of what will be truly transformational. Maybe it is seen as enough to be seen to be doing something. This is more concerning in governance terms when there also seems to be no room for voices which challenge openly the value of what is being done. Why would anyone not fully support something which is clearly doing the right thing?

There are clear dangers for dementia here which can be addressed by five collective actions at national and local levels

- use evidence better
- focus on fractures in the system
- integrate health, social care and housing
- increase critical discourse
- treat dementia as a long-term condition

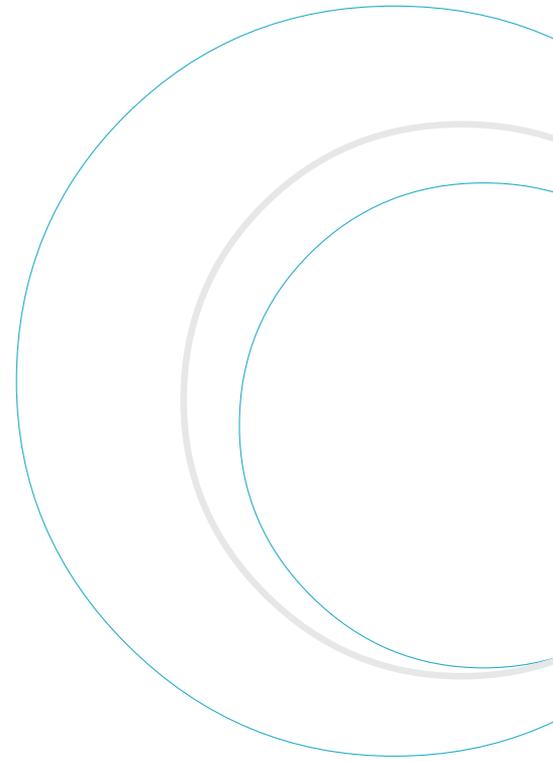
Use of Evidence

We have reached the point around dementia where we know a lot which, if it were applied more systematically, would make a massive improvement to the lives of those with dementia. This evidence matters. It is different from opinion. It is also different from research. It answers the question of what we know works and calls on wider knowledge than that labelled “dementia”. Knowing what is evidenced as effective can drive out poorly conceived or ineffective ideas before they do harm. This evidence does not seem to be reaching those who need it in policy-making roles or in front-line positions, judging by what is actually happening. Or if it is, then it certainly does not seem to be reflected in what is happening.

It is not clear why this evidential perspective - not just a UK one, but an international one - is not at the centre of policy framing or local action. Is it that people feel able to become “mini experts” in dementia with the minimum of training and knowledge – something inconceivable around other conditions?

Or is the problem in the way dementia is conceived – as a threat, a terminal condition, and one without hope rather than a long-term condition, where there are already plenty of models of progressive improvement?

For over 20 years the Dementia Services Development Centre, along with others, has advocated for an evidence-base on dementia improvement. There is an argument that an easy-to-access evidence base, independent of government or government agencies, is likely to be far more transformational than all the initiatives of the Prime Minister’s Challenge put together.



Knowing what is evidenced as effective can drive out poorly conceived or ineffective ideas before they do harm.

Fractures in the System

If evidence matters, so does diagnosis of where obstacles and problems lie in making progress. The Dementia Services Development Centre has undertaken diagnostic work across the UK which shows that the following fracture points can and are preventing forward momentum around dementia:

- failure to identify those with dementia – especially by GPs and within acute settings
- underuse of assessment tools at all key points in the system – different doctors seem to be unable to agree where, when and how assessment should be made and non-medical staff are not being used to undertake diagnosis
- confidence by professional staff to know what to do once a diagnosis of cognitive impairment has been established – leading to inaction and/or shifting of responsibility between professional silos
- low levels of basic knowledge in front-line staff – this is not being addressed by the current programmes of “dementia awareness” training; it requires “dementia response” – what to do and how
- lack of cohesion and connectedness – individual parts of the health and care system continue to develop initiatives in separation, and feel frustrated by the lack of action by others on whom they depend
- dysfunctional core processes – for example discharge planning which follows a mechanistic sequence of procedures which could be addressed earlier and in parallel
- lack of scale – there is a mismatch between the effort and resource devoted to dementia and the numbers
- failure to understand the economic case – the way dementia is currently being addressed is not only providing unacceptable care and increasing avoidable morbidity it is doing so at an unnecessarily high cost
- The need to “comply” with the national Dementia Challenge – creating a sense that accountability is upwards for specific schemes rather than about generating local solutions with local staff and the public, influenced by evidence of what works
- lack of clarity on responsibilities – there seem to be understandable confusion between key stakeholders about responsibilities and resources in the new landscape of health, housing and social care at all levels
- Lack of 24/7 information on dementia for carers and staff – leading to lack of confidence and isolation.

The most important obstacle remains inertia in the system, in spite of or even because of the national drive. Dementia, cutting across silos (health, social care, housing) and working across organisational boundaries, could provide an exemplar of a new, fully-connected strategic approach to social provision. We know of nowhere where this driving aim has been expressed or pursued. Instead there seems more to be a slavish following of a small number of national requirements (health and social care) and a justifiable sense of exclusion from policy (housing).

Health, Social Care and Housing

Housing is central to the future of provision for people with dementia and their families but there is little or no evidence of a collective approach being taken across health, social care and housing to think through future services. This is not a matter just for housing on its own. More work needs to be done to develop a positive framework for change which allows individuals to down-size as appropriate but then stay and have any care that they may need come to them.

Housing and housing-related services have a key role to play in supporting people with dementia and their carers and in improving the quality of health and social care services on offer. Given that many people say that the ability to continue to live at home is really important to them, access to information and advice is critical if people are going to achieve this aspiration. Early diagnosis and intervention can help to prevent crises, hospital admissions (which can so often lead to a deterioration in someone’s condition) or other longer terms forms of institutional care.

Housing design can be made to be dementia friendly. There are many things that people can do to their own homes to ensure that the lighting, acoustics, physical design and outdoor spaces are as dementia-friendly as possible. Specialist housing, such as extra-care housing can prevent a move to a care home. However, the development of housing-based solutions to the provision of support and care is falling behind demand. It has been said it is easier to get planning permission to build a nuclear power station than it is to get a care home off the ground. This perhaps typifies the way the current system fragments and prevents rather than enables services to be put in place where they are needed, when they are needed.



There are examples of how housing organisations have developed housing schemes for people with serious mental health problems and worked with local residents to create support for the scheme. In particular, there is a number of places where housing organisations have trained local residents to understand the behaviours that people with mental health problems may exhibit and the best way to respond. Such work could certainly be helpfully replicated to promote a better understanding of dementia at a community level. National policy needs to promote this more.

Critical voices

There is a noticeable absence of critical engagement around policy on dementia across the UK. This is worrying. The announcement of the Prime Minister's Challenge and the claims made for the value of specific initiatives and investments was subject to virtually no objective comment. There seem to be two main reasons. The way policy is being developed around big splash announcements is a problem. With the core civil service shrinking, third sector organisations and charitable think tanks are increasingly being used as proxies for policy expertise. In some senses this could be seen as a positive development – allowing different voices and experience to inform policy – but the sense around dementia is that in fact it is reducing critical scrutiny and may be compromising the independence and credibility of some of the organisations involved. How critical can you afford to be if you helped design the policy and are receiving significant investment as a result?

The announcement in England of a target of bringing on 1 million friends is perhaps the most telling recent example. There is little or no evidence in the UK or internationally that such a scheme will add any real value to the long-term experience of those with dementia. It is not surprising then that no information was used at the time of the launch or since to justify the priority placed on this investment. The 1 million figure is clearly head-line grabbing and arbitrary. There is no evidence that it can or will be achieved. The term “friend” was ill-defined at the launch. The plans for the programme itself were sketchy at best. The 1 million friends programme was based on an incomplete pilot in involving 50 people, and two groups run by market researchers employed by the Alzheimer Society. There is an absolute lack of rigour. It is policy based on “anything is better than nothing in the provision for dementia.”

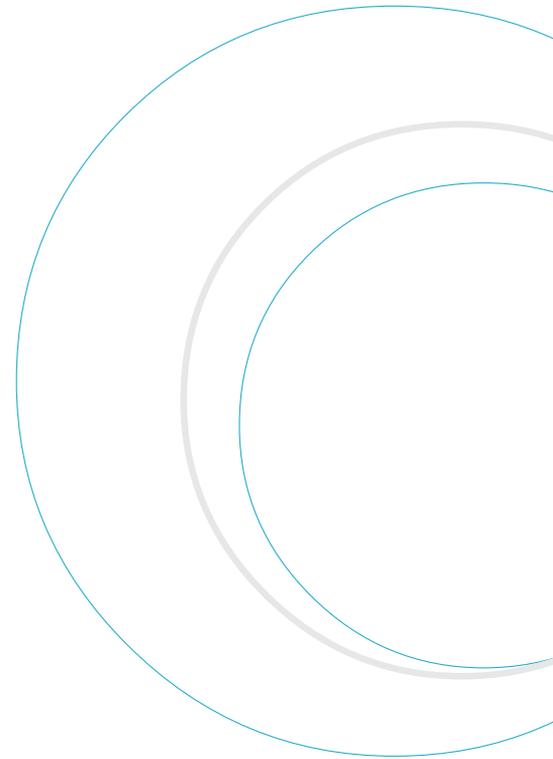
The Alzheimer Society like a number of national charities in the UK is positioned awkwardly as a user organisation, a service provider and a lobbying organisation and it is currently very close to Government on this issue. As a result of a policy they helped develop they have been commissioned, without any visible due process, to deliver the programme at the cost of £2.4m. The governance and ethics in operation here should give us pause for thought. Is there a non-virtuous circle here – government takes suggestions on trust without sufficient assessment but the state as a result invests directly in a struggling Third Sector and headlines are secured? This may not be seen as an inherently bad thing but in relation to dementia it is proving to be. There is a danger, as a result, that investments being made will not deliver anything like the value being attributed to them, but the Third Sector will hardly be in a position to provide an independent commentary. No-one will be looking for the hard data on impact. There is a real danger that the spending being made on the big splashes may simply prove futile. Worse still there will be a significant opportunity cost involved. We cannot afford this.

Dementia as a long-term condition

The Roundtable recognised what it saw as positive movement in attitudes to dementia. There are signs of a move from seeing people with dementia as an apocalyptic social burden to seeing dementia as something which can and must be taken up collectively. However the spectrum on policy approaches still has a feel of “being seen to do anything is better than doing nothing”, which perhaps explains why evidence is taking a back-seat.

More locally housing providers are understandably engaging with the progressive impact of dementia on people who are in their housing stock or in their care. Sadly some in housing still seem to view people with dementia as problematic leading to an “anywhere else but here” attitude. But in the best examples of the independent sector models of flexible provision are emerging, often unsighted or supported by public policy.

Overall people with dementia are still being too often being treated as having something which is hopeless, progressive and terminal. This remains the way policy is framed and underlines the cues given to front-line professionals and planners. This is a devastating, emotionally-driven and largely inaccurate way of looking at dementia.



A more constructive and accurate way of looking at dementia would be to emphasise its shared characteristics with other long-term conditions. This one change in approach could provide a more settled and less emotional approach to the future development of responses to dementia. Sadly this is unlikely to happen quickly as the Third Sector organisations, who have a perverse incentive to perpetuate the fear for fund-raising purposes, are at the centre of policy development. This is perhaps the most damaging consequence of the way a shrinking civil service, defaulting on trust to third sector organisations, runs the risk of missing the real revolution that needs to take place around dementia.

There is still the possibility of stimulating an evidence-based approach across health, social care and housing which looks at dementia as a long-term condition. But it looks like it will take an act of collective will by those whose voices are not being heard to make this happen.

Roundtable Conclusion

We believe that dementia should no longer be treated as a terminal specialism, but instead should be seen as a long-term condition.

We are concerned that the opportunity to achieve transformation change is being hampered by underuse of evidence on dementia and change and a lack of cohesive leadership across professional and organisational boundaries.

We see real dangers for ethics and governance of the third sector and for efficacy of policy in the current trends for using third sector organisations as a proxy for proper policy development.

We see real opportunities and an overwhelming need for housing, health and social care to work better collectively.

This may not be seen as anything new. But the stakes are high and the opportunity costs involved significant.

People with dementia deserve better. There are dangers for dementia which are lying just below the surface of the positive façade of big splash announcements. These do need to be heeded and addressed by anyone interested in really making this the decade dementia comes of age.

The Dementia Services Development Centre (DSDC) exists to improve services for people with dementia and their carers throughout the UK and beyond. We do this through research and teaching and by supporting workers and organisations that provide care for people with dementia. Our staff of academics, health and social care professionals, researchers and event organisers provide comprehensive dementia education and training, consultancy and research services. The Centre's flagship Iris Murdoch Building is a model for dementia friendly design. This open and welcoming environment provides inspiration for our team's work in designing and remodelling care homes for people with dementia. Research into understanding the needs of people and how to support them is central to our work. The Research Group are members of the University of Stirling who conduct research into our understanding of dementia and related matters. Their research projects help to improve the quality of life and services for people with dementia and their carers.

Dementia Services Development Centre • Iris Murdoch Building
University of Stirling • Stirling • FK9 4LA

t +44 (0)1786 467740
f +44 (0)1786 466846
e dementia@stir.ac.uk
w www.dementia.stir.ac.uk

The University of Stirling is a charity registered in Scotland, number SC 011159



Stimulating Thinking
on Dementia Policy