MEETING NOTE

"We're all in this together" – the impact of Big Society on the care of people with dementia
31 March 2011, London

In the third of a series of three seminars jointly hosted by the Arts and Humanities Research Council (AHRC) and the Nuffield Council on Bioethics (NCB), invited guests took part in a wide-ranging discussion arising out of issues raised by the Nuffield Council's 2009 report *Dementia: ethical issues*. This seminar focused on the Nuffield Council's argument that we all have a responsibility to support people with dementia, both within families and in society as a whole, and how a sense of solidarity can underpin policy decisions to improve care for people with dementia.

The event was chaired by Baroness Perry and included presentations by Professor Ruud ter Meulen (Director of the Centre for Medical Ethics, University of Bristol), Nick Gradwell (Head of Health and Social Care, Equality and Human Rights Commission), and Claire Goodchild (formerly National Programme Manager (Implementation), National Dementia Strategy, Department of Health).

This note outlines the key themes from the discussion, and the research policy proposals that were raised during the seminar.[1]

Key themes
The concept of solidarity
It was acknowledged that there are many different interpretations of the concept of solidarity and that this contributes to the complexity of the debate.
One important approach to solidarity was that it may be understood as an acknowledgment of a system where everyone is assumed to make a fair contribution to a collectively organised structure (e.g. the NHS) that guarantees equal access to health and social care for all members of society. The idea of solidarity itself could thus be associated with mutual respect, personal support, and commitment to a common cause. It may also be couched in terms of trust between individuals and the society in which they live.

The concept of solidarity in health and social contexts was noted in relation to people's equal access to health and social care. The value of solidarity underpins

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[1] The opinions outlined in this note are those of meeting participants, and not necessarily those of the AHRC or the Nuffield Council on Bioethics.

systems such as the NHS where everyone contributes a percentage of their income and receives health and social care in return, no matter what their income or risk of disease. Solidarity may also be understood to be a *moral* concept, and also an element of care *practices,* as it may motivate a person to provide care for someone who is in need.

The idea that solidarity can also be viewed as a sociological concept was also raised. In this context, a distinction can be drawn between 'mechanical' and 'organic' solidarity – a division first propounded by Emile Durkheim. Mechanical solidarity is epitomised by the attitude of the Amish community when, for example, a barn needs to be re-built after a fire. When this happens, the Amish community come together to re-build the barn in an automatic, 'mechanical' way. Conversely, organic solidarity refers to situations where solidarity is expressed through formal, organisational structures, for example in the guise of a valued and organised health and social care system. One could therefore question whether a (general) societal shift from mechanical to organic solidarity means that solidarity on a personal level has disappeared. However, in recognising the role of informal care as a 'new kind' of solidarity, it could be argued that personal accounts of solidarity remain.

This kind of solidarity, which is not enforced by the state, depends on the individual's free choice to act in a supportive way. This motivation to provide care for others in our society is very strong. However, it is not without problems, especially in the context of dementia care. For example, carers may be faced with challenging behaviour, which may become more pronounced as the dementia progresses. This raises emotional, but also ethical issues for carers; how, for example, should the autonomy of the person with dementia be preserved? How should the autonomy of the *carer* be preserved? It was noted that informal care can only work if there is sufficient *professional* care to partner the efforts of the informal carer in order for the two to form a care partnership. Moreover, it should be recognised that there is a limit to how much informal carers can do.

Solidarity and the role of the 'Big Society'
Solidarity is an important value in the organisation of health care systems, in personal relationships, and in informal care situations – which should be supported by professional care. However, it was felt that discussions about the idea of the 'Big Society' should not mean that all care should be shifted to the family; carers need support in terms of the information that is made available to them, and also – in order to maintain their own autonomy – respite provision. Moreover, it was argued that informal carers need support in the 'Big Society' in order for them to act in accordance with principles of solidarity, and also to encourage the continuation of their own functioning and flourishing as 'people'.

At a recent Thinktank organised by the Department of Health, which focused on Dementia and the 'Big Society', it was suggested that people with dementia

tend not to make a link between their experience of feeling isolated from their community and inequality.[2] However, it was argued that there are clear instances of people with dementia being treated unequally. Discussions as to how best to support people with dementia, should be framed in terms of helping maintain their identity. This approach, it was felt, could have a positive impact on people with dementia receiving equal treatment.

Moving from home to care home: the role of professional and community support

It was suggested that the widespread assumption that people with dementia will go into a care home is misguided. Early diagnosis and forward planning may assist in this assumption being overturned. It was argued that, generally, the best thing for a person with dementia is for them to stay in their own home for as long as possible. In order for this to be realised, however, professional support is needed for both the person with dementia and their family carer.

However, what counts as one's 'own home' may not always be straightforward, and where a person with dementia wishes to live may depend more on relationships than on their surroundings. An example was given where a person with dementia was asked where their home was, to which they answered "when I'm with you." In addition, it was noted that many people with dementia associate the idea of 'home' with a place that they lived in 50 years ago.

A recent report by the Alzheimer's Society – 'Support. Stay. Save.' – addressed the care of people with dementia in their own homes.[3] The quality of care people with dementia receive in their own homes is sometimes inadequate, a matter of some concern considering the fact that two-thirds of people with dementia live in the community. It was therefore suggested that those commissioning care for people with dementia and their carers need to consider enabling more community support services of a higher quality than the current norm.

The role of communities

Discussion drew attention to the specific role that communities can play in supporting people with dementia. It was argued that the stigma attached to dementia has been compounded by the removal or exclusion of people with dementia from community life. A distinction was drawn between the exclusion of those with dementia with people who have physical disabilities, who are – compared with a few decades ago – very much integrated into communities that have adapted to meet their needs.

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[2] Department of Health (2011) *Dementia and the Big Society: report from Think Tank 16 February 2011* (London: Department of Health), available at: http://www.dementia.dh.gov.uk/_library/Report_Dementia_and_the_Big_Society_Think_Tank_1 6_Feb_2011_final.pdf.

[3] Alzheimer's Society (2011) *Support. Stay. Save. Care and support of people with dementia in their own homes* (London: Alzheimer's Society), available at: http://alzheimers.org.uk/site/scripts/download_info.php?fileID = 1030.

Community development needs to be addressed in order to overcome the exclusion of people with dementia from their communities, and attention was thus drawn to examples of community action in other countries. The example of a Japanese community was cited, where people with and without dementia live alongside one another, enhancing the health and welfare of people with dementia through the use of supportive communities. In this model, if a person with dementia goes missing, a network of 70 residents is notified, and a coordinated approach to finding the person is launched. In response to this initiative, it was suggested that neighbourhoods can contributed to the support of people with dementia. For example, a member of the Alzheimer's Society is currently training shopkeepers and other service providers in the Bournemouth area to raise awareness of dementia. Participants also noted the work of the Alzheimer Café scheme, where carers and people with dementia are encouraged to meet and talk in an informal café-style setting. In the Netherlands, crèches have been set-up in care homes so that small children can be cared for by people with dementia. This encourages people with dementia to do something within the community. Care homes 'opening their doors' to the community in this way was felt to be a priority for improving dementia care.

The importance of language and communication
Several references were made throughout the seminar to communication, both in the context of communicating effectively with people with dementia, and also choosing one's language carefully in the context of dementia care.

An example was given where a woman – Professor Jones – received an early diagnosis of dementia and, following the end of a relationship, moved into a residential care home. After her move to the care home, it was argued that a process of 'enfeeblement' took place, undermining her own, formerly strong, identity. One way in which this enfeeblement was manifest was through the staff giving Professor Jones a demeaning nick-name. It was suggested that there should be a development of standards for how professional staff should behave towards people with dementia, for example by ensuring that patients are asked how they would like to be expressed. Similar standards have already been developed in the context of cancer care.

There was considerable debate as to the use of the term 'incarceration' of people with dementia who enter into care homes. On the one hand, this term may reflect people's experiences, because people with dementia are often clear that they do not want to move into a care home but are faced with a care system which has no other support or services to offer them. However, other participants felt that the term 'incarceration' was too strong, and that judgments about a person's care situation should depend wholly on their individual care circumstances. One attendee noted that care homes may reduce the loneliness and isolation felt by a person with dementia. Furthermore, it was suggested that people can be institutionalised in their own homes, and that it was dangerous to couch dementia care homes in language of 'incarceration' and 'putting people

away' as, for some people with dementia, care in a residential setting is entirely the right option. It was suggested that care homes needed to function differently so that they are no longer isolated units, but rather an integral part of communities. This, it was argued, may help to ease the guilt felt by carers when they have to make the decision to let the person with dementia go into a care home, and also lessen any suggestion that they are 'incarcerating' their family member.

A further point focusing on communication emphasised that relatively few voices of people with dementia are heard. For example, it was noted that a recent Department of Health initiative on user-led organisations did not exclude people with dementia but neither did it take necessary steps to *include* them.

The impact of fear
A survey recently found that getting dementia is one of people's greatest fears, and that people may avoid communicating with a person with dementia because they may not know how to respond to them appropriately. People with dementia may stop going out into their own communities and thus become marginalised, both because of the reaction of other members of the community, and also because they are frightened to do so. Dementia is often blamed for such situations rather than the shortcomings of society.

Enfeeblement and the removal of driving licences
The removal of driving licences from people with dementia was cited as a specific example of 'enfeeblement'. A question was raised as to how the DVLA addresses the issue of dementia, and whether the issue should be examined by central government. In principle, there is no blanket rule for the removal of licences; rather a visuo-spatial assessment is undertaken in order to check the person's ability to continue driving safely. However, there may be misconceptions among some GPs that a diagnosis of dementia should result in the instant removal of the person's driving licence.

Self-management and personal budgets
The provision of personal budgets – allocations of a budget to users of care services that they may control themselves – arose at several points during the seminar. Personal budgets assume that those who are in charge of them are competent consumers; that they 'buy' services with competence. However, at the point when the budget should be spent, many users are undergoing trauma, and may not be in the best position to make decisions about how to spend their budget. In the context of dementia, personal budgets for this group of people are often last on their list of priorities for local authorities.[4]

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[4] A Department of Health-led report on personal budgets and dementia will be published in the near future.

Financing care was also raised in terms of the *amount* available to older people. In many local authorities a person aged 65 and over is entitled to less money for their care than those under that age threshold.

Areas of research suggested by participants
- Re-visiting the idea of piloting a 'first aid' training course for dementia, mirroring physical and mental health first aid guidance, with the aim of enabling the public to be better equipped to engage with a person with dementia.
- Investigating the link between creative interventions for people with dementia and the impact those interventions may have on challenging behaviour, and the person's self-esteem.
- Examining the effectiveness of inter-agency collaboration in the context of dementia care.
- Using the disability movement in the 1980s and 1990s as a model with which to compare dementia. What can supporters of dementia gain from comparative work with the disability movement? Why is dementia, practically if not legally, separated from other disabilities?
- Examining the research that has been done in relation to advocacy for people with an early diagnosis of dementia.
- Investigating further the idea of stigma. Has the recent public profile of dementia resulted in people being frightened of symptoms? Is it the diagnosis of the disease, or its label and behaviours that are the stigmatising factor?
- Exploring what people with dementia can achieve in work and also in their communities, i.e. how they can and *do* play an active role in society. What is the impact of these achievements on stigma?
- Examining how education can help to decrease stigma.
- Research into the relationship and tension between memory and common perceptions of personhood, and on what can be done in societies to decrease stigma stemming from this tension.
- Further research into how we can make the communities in which we live better places for the person with dementia – for example, working with shopkeepers.
- Examining the impact on a person with dementia of the removal of their driving licence.
- Asking how models of good practice in care provision and support for carers can be promulgated so that lessons are learnt and put into practice. What are the barriers to learning lessons and putting learning into practice?