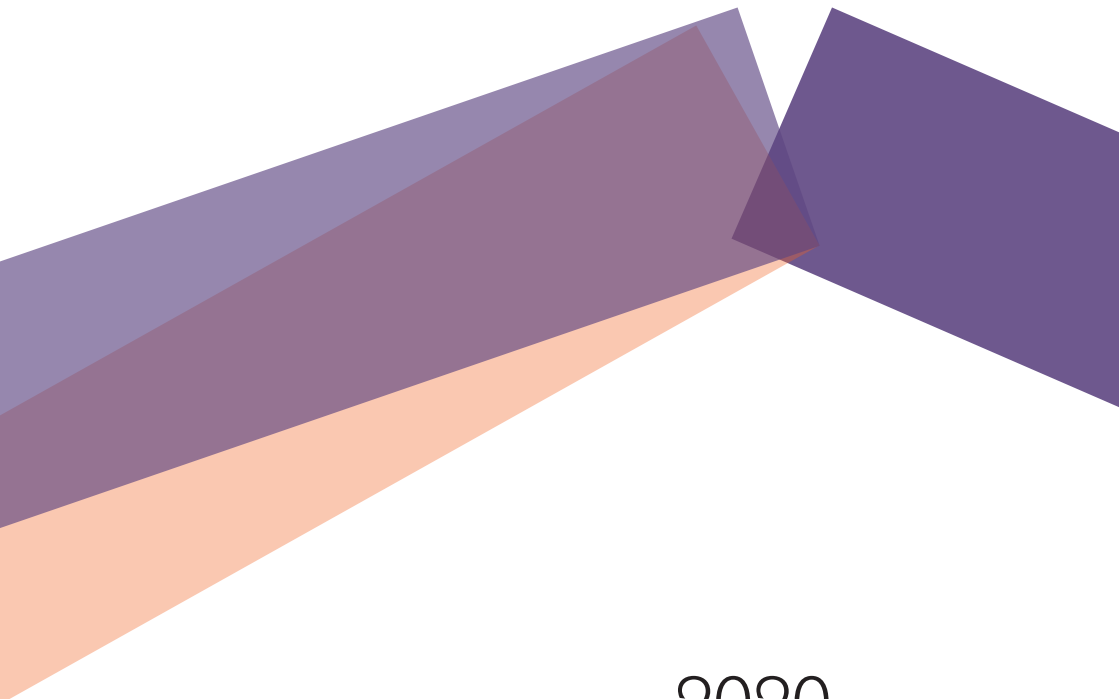


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Long term care for older people, social productivity and the 'big society': the case of dementia



2020
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at the **RSA**

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8 John Adam Street, London WC2N 6EZ
+44 (0)20 7451 6962

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Author

Sally-Marie Bamford is Assistant Director for Research and Strategy at the International Longevity Centre-UK. She read Politics and French at Nottingham University. An NCTJ accredited journalist, she has a Masters in Social Policy and Research from Birmingham University. Sally-Marie worked in the European Parliament for several years after graduation and has since held a variety of advisory and research posts in the charity and public sector, researching and writing on social care, workforce development and equality and human rights.

Dr Craig Berry is Head of Policy and Senior Researcher at the International Longevity Centre-UK and former Policy Advisor on Older People and State Pensions at HM Treasury. He also lectures on economic policy at the University of Warwick. He conducts research and policy analysis on the economic implications of population ageing, focusing on pensions, fiscal policy, and social care. He completed his PhD, on globalisation and UK trade policy-making, at the University of Sheffield in 2008.

Foreword

Europe is getting older. Getting our heads around the implications is a major challenge. As the Economist tells us, the ‘slow-burning fuse’ will have enormous financial consequences – a ‘huge headache’ for public finances.¹ In a recent paper for the 2020 Hub, Professor Howard Glennerster estimates the long-term, cumulative fiscal cost of demographic change across Europe at up to the equivalent of 10% of GDP for some countries.² A variety of changing needs will drive costs upwards, not least the need for the group of services we currently group together as social care.

The question of how we fund long-term social care has been partly opened up by a recent policy review from Professor Andrew Dilnot. On what basis should the costs of care provision be shared between individuals, families and the state? What should be the relationship between state and market in the provision of care services? How can a balance be struck between national guarantees, local population needs, and individual preferences?

These are vital questions. Yet they are not the only ones. As the baby boomer cohort enters retirement age, there are parallel processes at work, raising opportunities as well as challenges. What is the fairest way to tap into the resources of this affluent and capable generation? How will ‘third agers’ begin to re-shape the boundaries of work and retirement? Will new markets for innovation and personalised services be created to meet increasingly diverse demands?

The Coalition government – driven by a desire to cut public spending and pare back an ‘over-stretched’ welfare state – is paying real attention to these questions, if not yet producing all of the answers. Health, social care, pensions and welfare policy are all under review. Yet it is perhaps the most aspirational of their policy narratives – the Big Society – that could have the most significant impact on long-term social care.

¹ ‘A Slow Burning Fuse’ in *The Economist*, 25.06.09

² Glennerster, H. ‘Financing Welfare States: a new partnership model?’ paper for publication in Kippin, H. & Stoker, G. (eds) ‘The Future of Public Service Reform’ London, Bloomsbury Academic Press, forthcoming

The Big Society is – nominally at least – about mobilising the latent resources of citizens; encouraging collaboration and voluntarism; and engaging people in the delivery of new, bottom-up public services. There is much to like about this approach – not least the conviction that public services can do more to tap into the co-productive capacity of citizens and communities. But the missing piece is a coherent account of the role of the state. Pulling back and inviting society to flourish is not enough. Instead, we must ask how public services can become better social catalysts – supporting and nurturing communities, and delivering public services in partnership with the people that need them. This is what the Commission on 2020 Public Services calls ‘social productivity’.

In this thoughtful paper, Sally-Marie Bamford and Craig Berry argue that social productivity could provide a helpful framework for considering how to construct sustainable social care services. They remind us that these are services that have never fallen squarely within our Beveridge-derived welfare model. Many of the social assumptions that positioned them outside of the fold after the war – such as female domesticity – no longer hold, but in other ways the range of needs described under the heading of ‘social care’ remain too diverse, too social, too intimate to sit neatly within a welfare model that is entirely publicly provided and publicly funded, even if financial resources were more plentiful. A Big Society analysis is strong in recognising the innately social aspect of social care, but weak when it comes to considering the implications for public policy. How can policy be recalibrated so that it goes better with the grain of people’s lives and ensures better, more equitable outcomes?

Bamford and Berry argue that the shortcomings of the Big Society approach are revealed when confronted by the hard challenges of dementia care. Types of social care need that respond more readily to the ‘helping hand’ voluntarism of the Big Society have taken centre stage, while the formidable medical-social challenges of dementia care have been left out of discussion, even though dementia care constitutes a massive and growing proportion of our total care needs. As they point out:

“there seems to be a silent assumption...that when it comes to care [the Big Society] applies most to those with physical disabilities,

or older people experiencing age-related problems around frailty, lack of mobility or sensory loss. Such individuals need ‘a bit of help’ around the home, or support in getting ‘out and about’, but generally speaking are mentally well, and as such are receptive to care-related support services.”

But older people with dementia may require very different types of care and support from their families, carers and peers. The needs of people with dementia requires us to think differently about the way services are personalised, the way carers are supported, and the role of the central and local state in creating the conditions for safety and support in old age.

The Big Society debate risks glossing over these issues in its account of the capability and resources of citizens. Policymakers are right to point out the central and continuing role of informal or unpaid care. Yet without thinking seriously about the relationship between this ‘Big Society’ care provision and the public infrastructure and resources that should support it – thinking about social productivity – we risk undermining the care partnerships that are vital in supporting dignity and quality of life for our ageing population in future.

Henry Kippin & Paul Buddery

2020 Public Services Hub

Introduction

The notion of the ‘big society’ has been a major theme of David Cameron’s leadership of the Conservative Party (see Cameron, 2010). Essentially the big society is the centre-right’s cure for a society ‘broken’ in large part by an overbearing state. Similarly, those on the centre-left speak of ‘social recession’ – although they include the excesses of globalisation and power of finance capital, as well as the bureaucratic and managerialist state, in their diagnosis – and the ‘Blue Labour’ campaign borrows heavily from the big society narrative in outlining the importance of civic organisation and action (see Finlayson, 2010; Glasman, 2011).

The big society agenda is nowhere more relevant than in relation to long term care for older people. The Department of Health’s adult social care white paper refers approvingly to the big society and social productivity, as such making civic action central to both preventative care and partnership-based delivery of personalised care services:

“A Big Society [sic.] approach to social care means unleashing the creativity and enthusiasm of local communities to maintain independence and prevent dependency. Local councils should work to enable people, their carers, families and communities to support and maintain full and independent lives. This means unlocking the potential of local support networks to reduce isolation and vulnerability. Social care has a long history of building community capacity. A renewed emphasis on this goes well beyond the social care sector and must focus on what people can do for each other.” (Department of Health, 2010).

While the influence of the deficit reduction agenda cannot be entirely discounted, the government is also acknowledging in some ways that social care is not something that can be delivered by the public sector alone.

The focus here, however, is not principally on what role central or local government should have in the big society of care delivery. Rather, we consider, albeit briefly, how or whether the big society can deliver care for older people with dementia, given the enormous strain that dementia is

placing on traditionally designed public services. It may be more appropriate therefore to refer more widely to ‘social productivity’ as well as the big society. In a narrow sense, the social productivity concept is also about enabling non-state actors to do what the state cannot do, or cannot afford to do. In a wider sense, however, it is about recognising the limits of both state and economy in delivering public goods, and as such recognising the essential role of individuals, families and communities in defining social value and determining the interventions that will most effectively bring public goods about.

While it has not been explicitly acknowledged, there seems to be a silent assumption among those discussing care and the big society (or even the more expansive concept of social productivity) that when it comes to care it applies most to those with physical disabilities, or older people experiencing age-related problems around frailty, lack of mobility or sensory loss. Such individuals need ‘a bit of help’ around the home, or support in getting ‘out and about’, but generally speaking are mentally well, and as such are receptive to care-related support services. In contrast, dementia results in a devastating loss of cognitive and intellectual functions, often accompanied by changes in psychological and emotional states leading to depression, aggression and apathy, and straddles the frontier between health and social care. It may in fact be the case that social productivity has an even greater purchase in relation to dementia, given its intensely personal and progressive nature, and the already critical role of families in providing care for people with dementia. Yet the white paper contains only a single reference to dementia, as one of several service areas affected by Lancashire County Council’s user-centred commissioning initiative, and little attempt has been made by policy-makers to relate dementia to the big society agenda.

The first section of this paper considers the ‘zenith’ of long term care, that is, the apparent unravelling of the Beveridge settlement and the *de facto* positioning of long term care within the private or family sphere. It then looks at dementia in more detail, before outlining how the big society and social productivity concepts may be relevant (or not) to considering how dementia is treated and managed. The paper argues that while dementia is central to the crisis seemingly engulfing public services in the

UK – and long term care services in particular – which has given rise to an interest in the big society as an aspect of public service reform, it is not clear that a big society framework has been imagined with people with dementia in mind. The more expansive concept of social productivity may be useful in thinking about dementia care beyond the state, although limitations stemming from the nature of dementia syndromes remain.

1 The social care zenith

Long term care lies at the frontier of the welfare state. Formal care services are delivered by various facets of the state, most notably local authorities, or instead supported and organised by local authorities but delivered by the private or third sectors. But there remains no coherent approach to or even conception of long term care within public services and, as explored in the third section, familial care is the bedrock of the care system in most parts of the UK.

It seems that long term care is ‘the one that got away’ from William Beveridge, as he outlined in the 1940s a welfare state designed to address the five ‘giant evils’ of want, squalor, ignorance, idleness and disease. A deficit of long term care was not considered a giant evil, that is, a problem requiring large-scale public intervention. In defence of Beveridge, and of the Labour government led by Clement Attlee that implemented his plan, the provision of care has traditionally been the task of the private or family realm. Two major changes that could not have been foreseen in the 1940s have undermined this arrangement: the entry of women into the labour market (which reduces the supply of care, although the care burden remains predominantly with women, especially in relation to older people) and population ageing (which increases demand for care).

As a result, unmet need has become a significant problem. The Commission for Social Care Inspection (CSCI) estimates that 2.5 million older people need some form of care and support. Of these 2.5 million, 1.5 million people (approximately 60 per cent) have some shortfall in their care. 850,000 older people are deemed to have high levels of need (10 per cent of the total population of older people); in 2006/07 the CSCI estimated that 6,000 older people with intensive needs and 275,000 older people with less intensive needs were receiving neither formal care services nor informal care (see CSCI, 2009).

Does this mean that care should now be brought more firmly into the welfare state – supplementing the formal care services available and replacing the over-burdened informal sphere? Arguably this has been happening by default – leading to ‘lumpy’ provision – as these changes have unfolded. An additional reason, however, why long term care was not recognised by the

architects of the welfare state was the nature of care needs and care provision. The range of activities that could be defined as care is probably endless, given that meeting a care need is not about delivering a certain service, but rather producing a certain outcome, by various means. Needs themselves are in many ways amorphous. Care should therefore not be thought of as an intervention, but rather a 'type' of intervention that could in practice take many forms (see Berry, 2011; Kippin, 2010). This does not mean that care needs are not often severe and complex – and given the increase in dementia, more severe and complex than ever – but rather that the services required to meet these needs cannot be straightforwardly defined. As such, despite the stretching of supply noted above, informal care is becoming more important to the UK's care system: since the introduction of free personal care in Scotland, for instance, the provision of informal care has actually *increased* as formal provision has allowed informal carers to concentrate on providing wider care-based support (see Bell & Bowes, 2006).

It may be more appropriate therefore to think about a deficit of caring in terms of an activity performed by relatives and friends, in conjunction with professionals, rather than a deficit of care as a Beveridge-style public service provided predominantly by professionals. This deficit would represent a giant evil but cannot be overcome in any straightforward sense by a giant state. This is perhaps why the government, as noted in the introduction, has explicitly related the big society to social care. The big society agenda essentially advocates individuals and communities taking more responsibility for their lives and circumstances, in place of public authorities. It has various applications, such as reforming public services to enable delivery by the private and voluntary sector (and co-operatives and social enterprises), enabling more democratic oversight over locally constituted bodies such as the police service, and encouraging volunteering and philanthropy. Arguably, however, 'social productivity' is the more appropriate framework for assessing long term care beyond the state – not least because, as will be explored below, society is already very much involved in delivering care, in place of the state. Social productivity encourages us to think about how public services, citizens and local social institutions can combine more effectively. It recognises limits to the state but is not *a priori* anti-state; rather, it encompasses the view that value must be understood

more holistically than either the generation of commercial profit, on the one hand, or the (nominal) achievement of public service outcomes defined by public authorities on the other hand.

As such, long term care clearly informed the Commission on 2020 Public Services' thinking on public services reform; much of the experience drawn upon clearly relates to care provision, and this is reflected in the principles developed by the Commission:

- » 'A shift in culture' from social security to social productivity is necessary because to have a care need is not simply about not being able to afford a decent home, education or medical treatment, etc. – it is also about a lack of self-efficacy.
- » 'A shift in power' from centre to citizens is necessary because it is impossible to direct a nebulous array of services from the centre, even where that centre is local rather than national. Care needs will be different for each individual, so they and their families must be involved in design and procurement.
- » 'A shift in finance' is necessary for the same reason; as Emma Stone and Claudia Wood (2010) argue, we cannot separate the 'how' from the 'what' of care funding. Co-payment, private insurance and complementary currency models will help public authorities in determining the priorities for delivering public good, while enabling individuals to fund more subjectively-defined services. It should not mean that the poorest individuals are not assisted in making contributions to care funding. Lifecycle accounts, for instance, would improve knowledge of and accountability within public service financing – and should create demand for the kind of preventative measures that will be vital to addressing care needs before they arise.

Big society initiatives in care seem to embody this approach in some ways. The government's white paper and Commission on 2020 Public Services identified Southwark Circle as an example of the kind of community organisation that can help with care provision. Members of the Circle gain access to a range of user-initiated social activities, and can also purchase tokens for practical support to facilitate a healthy, mobile and independent lifestyle

from voluntary ‘neighbourhood helpers’. The white paper referred also to the concept of ‘time-banking’ and other complementary currencies, whereby individuals providing practical assistance and support within their communities can bank resources such as the time spent in helping others, and draw upon it in future in order to receive help from others when required. Indeed, many local authorities are now utilising sophisticated ‘slivers of time’ technology to match volunteers to older people in need of low-level support. This is not simply about mobilising the role of volunteers within (broadly defined) care delivery, but fundamentally also about providing services voluntarily as a direct, yet non-financial, way of funding the costs of one’s own care.

Yet it is clear that the main thrust of the big society has been related to the second principle, that is, a shift in power, and to a lesser extent the third principle, ‘a shift in finance’. There seems to be an assumption in big society thinking that ‘a shift in culture’, the Commission’s first principle, is a product of the other principles rather than constitutive of the big society in-itself: by taking power and finance away from the state, more capable and responsible citizens will emerge. More attention surely needs to be paid to how public services can enable individuals and communities to exercise meaningful control – or there is a danger that organisations in other sectors will replace the state but neglect to address questions of social value. The configuration of services must be able to fix and develop social networks and social capacity in the act of delivery; social productivity is therefore both an input and output from care provision.

In some ways, the increasing prevalence of dementia typifies the social care zenith. It creates increased demand for both medical care and social care, but as a large-scale societal need does not fit neatly in either category. Caring for people with dementia often falls to relatives – dementia is a medical condition, but demands a level and type of intervention that the health service cannot deliver alone. This places strain on traditional familial care, precisely when the old public/private boundaries of the Beveridge settlement are becoming unravelled. Is the big society the answer? It is hard to imagine that people with dementia were the kind of public service recipients envisaged by the government when the big society agenda began to form as an aspect of public service reform. Yet before this issue is addressed in more detail, it is necessary to take a closer look at dementia itself.

2 The case of dementia

Dementia directly affects over 750,000 people in the UK, and it is estimated that this number will soar to over one million by 2025 (Alzheimer's Society, 2007). This number may in fact represent an under-estimate, given that diagnosis rates are lower in the UK than in many other European countries. Dementia predominantly affects persons aged 65 and over, with an estimated 6.4 per cent of people in the age group afflicted with the disease, but as many as one in five persons aged 80 years and over afflicted (Lobo et al., 2000; Royal College of Psychiatrists, 2009). After the age of 65, the risk of dementia doubles for every additional five years of life (World Health Organization, 2006).

Studies have shown that the prevalence of dementia syndromes, specifically Alzheimer's disease (AD), is increasing disproportionately among women – which pattern appears to be a cross-cultural and cross-national phenomenon. Two-thirds of people currently with dementia in the UK are women (Alzheimer's Society, 2010). AD is by far the most common type of dementia in the UK: approximately 62 per cent of all dementia cases are categorised as AD, followed by vascular dementia (VD) at 17 per cent; however, mixed pathologies of dementia are more common than 'pure' pathologies.

Dementia is viewed as one of the most disabling of all chronic diseases. The middle-to-late stages of the disease, in particular, signal a loss of autonomy, physical and cognitive function, and independence for the majority of afflicted individuals. The most recent *Global Burden of Disease* report published by the World Health Organisation contends that dementia contributes to 0.8 per cent of all 'disability adjusted life years' worldwide, 1.6 per cent of 'years lived with disability', but only 0.2 per cent of 'years of life lost' (see ADI, 2009). More commonly associated with disability and cognitive impairment, dementia is gradually becoming recognised as an underlying cause of death. The dementia-specific mortality rate has been found to be twice the rate of people without dementia, controlling for comorbidities and socio-demographic factors. Approximately 60,000 deaths a year in the UK are directly attributable to dementia (Knapp and Prince, 2007). Dementia currently costs the UK economy £23 billion per year, which includes social care costs of £9 billion (40 per cent of total cost),

health care costs of £1.2 billion (5 per cent), informal care valued at £12.4 billion (55 per cent), and an additional £29 million in productivity losses; this cost is greater than the cost of cancer and heart disease combined (see ILC-UK, 2011).

Thus we can no longer remain indifferent to the profound challenges that dementia poses regarding public health, social protection and future economic stability. In fairness, politicians and policy makers have responded in the past five years, and the dementia agenda has risen from a political lacuna to become a fulcrum of public policy debate across the UK and indeed Europe. This advance has in no small part been linked to campaigning and high-profile lobbying of national charities such as the Alzheimer's Society and Alzheimer's Research UK (formerly the Alzheimer's Research Trust). The charities have effectively capitalised on increased public and celebrity support for dementia and garnered high profile ambassadors, such as the distinguished fantasy and science fiction writer Terry Pratchett to exert pressure on the government. Moreover, high-level dementia champions within the political arena – members of the All Party Parliamentary Group (APPG) on Dementia in particular – have been instrumental in pushing for a co-ordinated strategy.

This concerted and collective effort culminated in the publication of the National Dementia Strategy in February 2009, marking the commitment of the then Labour government to address the care and treatment of people with dementia. It set out a road map for improvement which focuses on three key areas: improved awareness; earlier diagnosis and intervention; and a higher quality of care. Seventeen objectives were identified within the three areas. The devolved governments in Scotland, Wales and Northern Ireland responded similarly: a National Dementia Strategy was introduced in Scotland; a 'Dementia Vision for Wales' was announced; and a national strategy is pending in Northern Ireland.

Although the current coalition government has endorsed the National Dementia Strategy, considerable uncertainty, and arguably quiet scepticism, remains regarding how much of the strategy can be implemented in a climate of growing fiscal austerity. Yet the problems stem from before the 2010 general election. In January 2010 the National Audit Office (NAO) (2010) argued that the strategy and implementation plan had fallen short

of its ambitions and was at risk of failing to deliver on key milestones. In particular, the NAO report highlights the Department of Health's failure to make dementia a national priority target for the NHS. Primary care trusts have consequently not viewed dementia as a 'must do' issue. The NAO report found a lack of local leadership and ongoing shortfalls in training, and stated that the Department of Health had underestimated the strategy's costs. Indeed, concerns over costs continue to dominate policy and political discourse. As the report recognised, without adequate cost/benefit research in this area, there is a high risk that decisions made locally on prioritisation and service design will not be sufficiently well-evidenced or informed.

With continued resource constraints on local authorities and cuts to frontline services for older people already underway, it seems likely that the level of unmet need is set to increase. Yet this is complicated by the coalition government's vision for cutting back the role of the state in the name of the big society. While it may be a laudable objective, it remains to be seen how disempowered, marginalised or vulnerable members of the community, such as those individuals with dementia (whose support from the state has been inadequate, rather than overbearing), will fare as the state retreats further. Dementia and the big society is a veritable policy quagmire; in the following section we consider, albeit tentatively, how this relationship should be conceived and, where possible, fortified.

3 Dementia and the big society

3.1 Informal care

In the UK, as in many settings across the world, the bedrock of dementia care is provided in the form of informal care by family and friends. As such, in one important regard, the big society is already very much a feature of dementia care. Without informal care by friends and relatives of recipients there would be no care system in the UK. In providing care valued at around £119 billion, informal carers' role in funding care for older people, albeit by non-financial means, is crucial (Buckner and Yeandle, 2011). Around 14 per cent of this value comes from the contribution of carers for people with dementia (ILC-UK, 2011), equivalent to around £17 billion (the value of dementia-related informal care cited above, £12.4 billion, was based on 2007 calculations). Given the significance of this contribution, it is probably unfair to refer to this as 'informal'. However, the main alternative term, 'unpaid' care, is complicated by the fact that many informal carers do receive financial support through the benefit system – and many more should do so. We use the term 'informal' here to distinguish this form of provision from care provision by professionals – but it should be recognised that informal care provision is a far more important component of long term care than formal care provision.

Informal carers currently receive very limited support from public authorities. Carers' Allowance (CA) is a benefit available to individuals providing care for more than 35 hours per week for someone in receipt of certain disability benefits. CA is not available to people who earn more than around £100 per week, or are in full-time education. Pensioners in receipt of basic state pension £59.30 or over per week are also unable to receive CA, but may be passported onto the carers' premium within Pension Credit and other means-tested pensioner benefits. Around half a million people are in receipt of CA, which costs the state around £1.5 billion per year. Some care recipients pay for carers through direct payments (a forerunner of personal budgets) but are only permitted to employ relatives in exceptional circumstances. As James Lloyd (2010) has argued, CA assumes poverty-level earnings, and is therefore 'effectively meaningless' as an earnings-related benefit.

Caring responsibilities may create significant financial problems for informal carers. Qualitative research conducted by Hilary Arskey et al (2005) for DWP found that carers find it difficult to combine work and caring, leading to 'de facto' retirement for many. Planning ahead, and returning to work once caring responsibilities end, are particularly problematic. According to a survey undertaken by the NHS Information Centre (2010), around 12 per cent of people provide some informal care, representing around 5 million people in England, for adults with a disability or illness. Around half of carers provide more than 20 hours per week of care. The survey findings showed that caring responsibilities can have significant negative effects on many carers: more than half said that their own health had worsened since the onset of caring responsibilities, and more than 40 per cent said that their personal and social life had been negatively affected. A survey of the informal carers of self-funders commissioned by the Putting People First Consortium found this group faced particular difficulties over lack of information and guidance, as well as financial concerns. Interestingly, carers portrayed greater levels of anxiety than care recipients themselves (see Melanie Henwood Associates, 2010).

Any outline of the contribution made by informal carers perhaps leads logically to the conclusion that the state should intervene to relieve the burden. This point of view is understandable and in many ways justified. According to the IPPR (2010), however, around 40 per cent of people would prefer their relatives and friends (rather than professionals) to provide their care. While the proportion surveyed favouring professionals was slightly higher, the same survey found significant confusion about where the boundary between health and social care lies; clearly, if people assume care encompasses health services, in a narrow sense, as well as social care, they are unlikely to favour de-professionalisation. Therefore, it is fair to say that there is strong support among the public for the continuing role of informal carers in care provision, although this is notwithstanding the support that exists simultaneously for increasing professionalisation in care provision. Indeed, part of the problem with the big society narrative is that it tends to juxtapose formal and informal provision; in terms of long term care, and dementia in particular, the two should not be seen as either/or.

3.2 Socially productive dementia care?

It is not clear that the array of actors grouped together under the big society banner have the resources or expertise in relation to dementia (or even the inclination) to remedy the problems associated with dementia care, in the absence of the state or traditional public services. While familial care already plays a crucial role, it should not be assumed that informal carers will be able to continue prop up an ailing social care system for people with dementia, which is heaving under the weight of increased demand.

Indeed, it must be recognised that informal carers, and certainly people with dementia, often overlook the symptoms of dementia. A lack of recognition of the symptoms of dementia, the severity of symptoms, and denial and fear are significant barriers to early diagnosis. Similar sentiments have been reported by carers or close family members, who may recognise that the individual they care for is suffering from some form of cognitive impairment, but decide not to seek professional help. It is often only at a point of crisis, for example when an older person is found wandering away from their home – a common symptom of dementia – that help is sought. Across Europe, 58 per cent of carers simply identify the symptoms of dementia as a normal part of the ageing process (Bond et al., 2005). Higher diagnosis rates are often found in countries where the ‘normal ageing’ explanation is challenged – as in the Netherlands (Vernooij-Dassen et al., 2005).

The APPG on Dementia, referred to above, recently released the report *The £20 Billion Question* following its inquiry into ‘improving lives through cost-effective dementia services’. The report advocates a move towards community-based services, not least to aid prevention of dementia, or more precisely preventing the need for the acute health and care services often associated with the progression of dementia. However, while this conclusion seems to echo the big society agenda, the report in fact does not identify non-state actors as the most important cog in community-based provision. Instead, the report refers most to the importance of an enhanced role for GPs in diagnosing dementia, the emergence of ‘key workers’ to help people with dementia navigate the array of services providers at the local level, and the provision of centres that enable respite care for informal carers. Research into dementia is hugely under-funded, especially in relation to other conditions.

Another barrier to a stronger role for individuals and society in dementia care is the stigma associated with dementia syndromes. Even where dementia is understood, it does not appear yet to have achieved a level of social acceptability comparable to other conditions such as cancer or, perhaps to a lesser extent, people with physical disabilities. The persistence of stigma among society in general underlines the need for professional dementia care services. Of course, we would expect stigma to have a lower impact in relation to familial care – yet familial care, as discussed above, is already a significant feature of dementia care. Furthermore, the role of familial care does not negate the need for professional care, due to a relative lack of understanding of dementia syndromes. Having said this, simply because diagnosing dementia is difficult for families and communities, does not mean we should accept this scenario at face value. It is surely necessary to improve society's understanding of dementia, and overcome stigma. Yet it is not clear that this will be achieved through a retreat of the state.

Alice Sachrajda's (2011) briefing on dementia care in London, part of IPPR's 'Older Londoners' project, does advocate an enhanced role for the voluntary and community sector in dementia care. Sachrajda argues that the VCS may be best placed to provide training for commissioners, advocacy, and support for informal carers; she also envisages a strong role for the VCS in awareness campaigns. Interestingly, however, the briefing also advocates a stronger regulatory role for public authorities in relation to VCS dementia services. This would improve the sector's capability and reliability, assisting commissioners of services.

Sachrajda argues that some older Londoners with dementia welcome the big society, at least in a rhetorical sense. They often feel isolated and under-stimulated, and associate the big society with increasing levels of social interaction. Clearly, big society initiatives such as increasing volunteering rates could help to enhance the interaction between people with dementia and the community in general, as well as helping to challenge stigma and provide forms of low-level support. The recent APPG on Dementia (2011) report also highlights the importance of peer-based support in this regard. In February 2011, the Department of Health, University of Bradford Dementia Group and the Alzheimer's Society convened a 'think tank' event involving various stakeholders to explore issues

around dementia and the big society.³ There was a strong sense from the participants that a lack of community participation is a significant problem for people with dementia, and in this sense the big society agenda was endorsed. However, the emphasis was not on the state withdrawing from dementia support; instead, the group called upon public authorities to do more to create spaces where people with dementia felt safe physically and socially. The group also called for public services to be organised around the notion of fairness – there was concern among some participants that the big society agenda had moved away from this principle.

It seems apparent therefore that there is more that individuals and communities could be doing to support people with dementia, and that the VCS could play an enhanced role in dementia care – not least in supporting the public sector. But it is questionable that such developments will have a significant, positive impact on dementia simply through the state getting out of the way of non-state actors. Responding to the challenge of dementia will require enormous investment by the state in coming decades, and even nurturing forms of community-based support and the capability of the VCS in relation to dementia will require the resources and co-ordinating function of public authorities. In qualitative research on people with dementia conducted by Innovation in Dementia (2011) in advance of the ‘think tank’ event referred to above, people with dementia – almost without exception – blamed dementia for their inability to cope in mainstream society, rather than shortcomings in their community (although they did also recognise the need for more local support organisation and activities, and an awareness campaign to challenge stigma).

For these reasons, it may be more appropriate, when looking beyond the traditional Beveridge settlement, to think in terms of social productivity rather than simply the big society. The big society concept encourages us to celebrate the role of informal carers in providing dementia care and long term care more generally – but social productivity challenges us to augment it. Social productivity also encourages us to consider how to

³ It should be noted that the various publications associated with this event appear not to be available online currently. They were accessed by the authors in spring 2011 from the South West Dementia Partnership website, where information about the event remains available (see www.southwestdementiapartnership.org.uk/2011/03/dementia-and-big-society-think-tank).

break down the boundaries between different aspects of public provision – challenging the frontier between health and social care will surely be vital to improving dementia care. While this idea has not been entirely absent from the coalition government’s plans, it is clear that the main interest of the big society concept is altering the balance between the public sector and other sectors – social productivity has no in-built anti-state bias, therefore encouraging us to consider how to better utilise (and where necessary enlarge) the resources of the public sector as well as enhance the role of the private sector and VCS in care provision. A think-piece assembled by Claire Goodchild of the Department of Health and Simon Rippon of the Department of Health’s North West Joint Improvement Partnership in advance of the February 2011 ‘think tank’ event advocated an ‘assets based approach’ to public service reform in this regard, whereby all stakeholders (people with dementia, communities, the private and voluntary sectors, and the public sector) conceived of their role as nurturing by various means the assets that enable communities to cope with dementia, rather than simply meet their own narrowly-defined objectives. This drew some support from think tank participants, although the main demand seemed to be joined-up delivery between health and social care providers in the public sector, although it is worth noting that user-led services would be a key means to achieving this.

One area where the big society and social productivity concepts overlap substantially, however, regards the move towards direct payment and personalisation, first initiated under the previous government. While it is beyond the confines of this paper to discuss all the drivers behind this new paradigm of social care, it is evident direct payments and personal budgets are viewed by many across the political echelons as a panacea for delivering greater choice for social care users, while at the same time containing the costs of long term care. In recent years, however, very few people with dementia have been eligible for direct payments; only 0.1 per cent of older people in receipt of direct payments in England had dementia, in a mild-to-moderate form (Davey et al., 2007). This is partly due to barriers within the system and the inherent complexities embedded within it. While the Alzheimer’s Society supports the personalisation agenda, it acknowledges that personal budgets seem to work best for individuals

with stable or predictable conditions, or who are able to make informed choices about their decisions. The cognitive impairment associated with dementia clearly represents a problem in this regard, yet so too may be the attitudes and culture of social care professionals, who are considered by some to be reluctant to explore how direct payments can work for people who lack capacity (see Alzheimer's Society, 2011). The APPG on Dementia (2011) recommends further studies to better understand the benefits and risks of personalisation for people with dementia. There are clearly wider questions around how personalisation can be adapted and modified to respond to the needs of this specific cohort of users, although it seems likely there are inherent limitations in relation to personalisation and dementia, undermining a key aspect of the big society in care provision but perhaps also the more expansive social productivity concept.

Conclusion

The dementia policy debate in the UK largely focuses on the fiscal elements of public policy, such as what dementia will mean in terms of increased spending for health and social care systems. Slowly, however, as the population ages – and the client base of the welfare state follows suit – dementia is being discussed in the same terms as other aspects of adult social care provision. Policy-makers and stakeholders are starting to think about the treatment of people with dementia in terms of independent living, preventative care, community-focused interventions, quality of life, etc. The concept of the ‘big society’ has the potential to sit relatively comfortably at the policy intersection of these agendas. Clearly, public and policy discourse should not simply frame individuals with dementia as passive recipients of care, but rather encourage policy and practice to enhance and foster dignity and quality of life for people with dementia for as long as possible.


The big society could be integral to this vision. But because the implication of the big society thus far has been a juxtaposition of state-directed services with personalised or community-based services, it is not clear that the big society has a great deal to offer a complex area of policy in desperate need of greater public investment and attention. This is not to say that the Beveridge approach to the welfare state should be transposed onto the long term care arena, or onto people with dementia in particular. There is certainly a role for individuals, families and communities in dementia care – as the crucial role of informal carers already demonstrates. But it may be necessary to move towards the more expansive concept of social productivity, so that we can think more holistically about how to mobilise a range of public and private resources in long term care provision, not least to provide grounds for greater public support for informal carers of people with dementia.

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2020 Public Services Hub at the RSA
8 John Adam Street
London WC2N 6EZ
+44 (0)20 7451 6962

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