HOW CAN AND SHOULD UK SOCIETY ADJUST TO DEMENTIA?

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This paper explores the application of the social model of disability to dementia. This involves looking in some detail at what this social model is, and where it has come from. This paper brings together the authors' respective interests in disability and ageing, and our respective training in disability studies and health and social geography.

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Background

Our paper sets out to address the following themes:

- the development of conceptual/theoretical thinking – especially looking at the social model of disability – and its relevance to dementia. Attention is paid to social diversity and equity;

- social attitudes and understanding – opportunities and barriers. Here the focus is on disablism and ageism – and the degree to which these overlap;

- the nature and development of services – thinking beyond the usual health and social care boxes – *thinking spatially*;

- the empowerment and involvement of people living with dementia.

The social model of disability

A small but growing number of researchers, writers and activists have recognised the appropriateness and utility of applying the social model of disability to the experience and politics of living with dementia (Proctor, 2001; Blackman *et al.*, 2003; Dorenlot, 2005; Beattie *et al.*, 2005; Davis *et al.*, 2009; Brittain *et al.*, 2010; Boyle, 2014). The JRF question 'How can and should UK society adapt to dementia?' invites social model thinking by suggesting that the responsibility to adjust rests with society rather than with individuals who have dementia.

The social model of disability was named by the disabled activist and writer, Mike Oliver (1983), in his attempt to capture the novel ideas about disability developed by disabled people themselves in the 1970s — especially those who formed the path-breaking organisation the Union of the Physically Impaired Against Segregation (UPIAS, 1976). Core to the novel ideas developed by Paul Hunt, Vic Finklestein and others in UPIAS was the proposition that disabled people were socially disadvantaged not by their impairments[1] itself but by the negative responses of people deemed normal by doctors and others in authority. In this way, UPIAS drew attention to a form of social relationship between disabled and non-disabled people predicated on social inequality, a relationship that makes its presence felt in a number of ways: in interactions between individuals; in the rules and practices in social institutions like schools and hospitals; and in solidified structural forms such as built environments and systems of travel. This perspective contrasted markedly with the taken-for-granted biomedical view: that being impaired is an abnormality that inevitably causes major problems and limitations in the lives of 'the afflicted'. It also contrasts with the commonplace pity perspective: that disabled people are to be pitied because their damaged bodies and minds stop them participating in normal activities.

Oliver's formulation of the social model of disability was a shorthand expression of the UPIAS view, and drew immediate attention to the social barriers erected by the non-disabled in all social arenas. Put another way, the model captured the idea that people with impairments are a socially oppressed group in industrial societies:

> *Thus we define ... disability as the disadvantage or restriction of activity caused by a contemporary social organisation which takes no or little account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities. Physical disability is therefore a particular form of social oppression. (UPIAS, 1976, pp.14)*

It was not long before people with forms of impairment other than the straightforwardly physical began to question their apparent exclusion from this UPIAS and initial social model formulation. With the subsequent development of the disabled people's movement (DPM) and disability studies[2] in the 1980s and 1990s, the case was made —and won — that people who lived with sensory or intellectual/cognitive impairments (principally learning difficulty) were also disabled people because they too encountered social barriers erected/practiced by the 'normal' (Barnes, 2012). Further extensions of the boundary of who counts as disabled have occurred in the 1990s and 2000s; people with chronic illnesses and mental health problems are now included in the community of disabled people (Walmsley, 1991; Beresford, 2002). In this way, the social model of disability is seen to apply to a growing proportion of the population with lifelong, acquired or attributed impairments, as Oliver's more recent summary suggests:

> *In the broadest sense, the social model of disability is about nothing more complicated than a clear focus on the economic, environmental and cultural barriers encountered by people who are viewed by others as having some form of impairment – whether physical, mental or intellectual. The barriers disabled people encounter include inaccessible education systems, working environments, inadequate disability benefits, discriminatory health and social support services, inaccessible transport, houses and public buildings and amenities, and the devaluing of disabled people through negative images in the media – films, television, and newspapers. (Oliver, 2004, pp. 21).*

Because of its conceptual simplicity, the social model of disability soon became a banner headline for the DPM in the UK, and has proved its worth as an extremely effective tool in campaigns for disability rights since the 1980s (Campbell and Oliver, 1996). Achievements of particular note in the struggle for disability rights and anti-discrimination legislation are the Disability Discrimination Acts (1995, 2005), the report by the last Labour Government *Improving the Life Chances of Disabled People* (Cabinet Office, 2004), and the introduction from the 1990s of financial arrangements designed to facilitate independent living – namely direct payments and personal budgets (Pearson, 2012). Evidence for the significance of these developments is clearly articulated in pronouncements by the Equality and Human Rights Commission (EHRC), formed in 2007, which laid innovative conceptual foundations for the recent Equality Act 2010 and the follow-up Equality Duty, now in force in England, Scotland and Wales.

Given this background and history, it is not surprising that people with dementia were eventually identified by a few researchers and activists as another set of disabled people to whom the social model should apply. The impairments[3] and impairment effects[4] that are associated with dementia are viewed as foundations upon which social barriers are erected by the non-disabled – whether this is done purposively or entirely innocently and in good faith. Adopting the social model of disability encouraged researchers to look more closely at the everyday experiences and perspectives of people with dementia (Blackman *et al.*, 2003; Dorenlot, 2005; Beattie *et al.*, 2005; Davis *et al.*, 2009; Brittain *et al.*, 2010). What is disappointing, however, is the relatively small number of such studies, and the peripheral nature of this work within disability studies. The latter no doubt arises from two weaknesses of note in disability studies in the last 40 years: the tendency to ignore or sideline older people and their particular social interests (Priestley, 2003), and the failure to understand and take account of the needs and interests of younger people (under 65 years old) with particular types of impairment such as dementia. These tendencies have been compounded by the starting point of most gerontologists, psychologists and many social scientists: that is, seeing dementia in strictly biomedical terms.

However, there are a few writers and researchers in disciplines such as social psychology who have adopted radical perspectives on dementia. For example, Tom Kitwood's (1997) ideas about personhood insist that we look at and recognise 'the person *with dementia*' and not focus on 'the person with dementia'. This kind of approach asserts that while we cannot escape the fact that an individual has dementia, and that this will impact on how they act and respond to people, and on what they can and cannot do, the individual is not defined by having dementia. In other words, the personhood perspective reminds us that people with dementia are still thinking and feeling individuals, with different personal histories, experiences, likes and dislikes. This implies that we should respect, value and celebrate what they can do rather than define individuals by their dementia; to do the latter leads to the medicalisation of individuals, and their relegation to demented body status.

Those writers and researchers who have applied the social model of disability to dementia have identified and highlighted the presence and operation of social barriers in the lives of people with dementia (see especially Blackman *et al.*, 2003; Dorenlot, 2005; Beattie *et al.*, 2005; Davis *et al.*, 2009; Brittain *et al.*, 2010). The impairment effects associated with dementia in individual cases – especially in the early, middle or late stages involved – means that the social barriers in

evidence vary in the profundity of their disabling consequences. Put another way, impairment effects and disablism interact, with differential outcomes.

Examples of social barriers at work among people with dementia are:

Individual attitudinal and behavioural barriers

- lack of understanding of the impairment effects that come with the stages of dementia on the part of some non-disabled people (e.g. formal and informal carers, family members, general public, young people);
- lack of sympathy and tolerance on the part of some non-disabled people;
- failure to recognise the practical difficulties faced by people with dementia (e.g. difficulty recognising places and people, way-finding, locating items) – especially in middle and late stages of dementia;
- failure to understand how easy it is for anxiety, fear and uncertainty to take hold in the minds of people with dementia – e.g. in unfamiliar surroundings and settings;
- failure to find ways to communicate with people with dementia, especially where spoken language is minimal or absent;
- failure to recognise and respond to the non-verbal ways that people with dementia use to try to communicate;
- misrecognition and misunderstanding of behaviours and expressions displayed by people with dementia – e.g. these may be wrongly attributed, in an ageist fashion, to 'just being old';
- failure to ask people with dementia what they want, how they feel, what would help to improve things in their lives etc., that is, treating them as passive and dependent;
- cruelty, violence and abuse directed at people with dementia;
- lack of respect, dignity and compassion – at all life stages, including during end of life care.

Barriers that become embedded in institutional and collective practices

- failure to design or adapt items, interiors, buildings, and external environments like streets and gardens, to support people with dementia enabling them to remain active, engaged and comfortable. This requires consultation with users, careful planning, flexibility and the creative use of technology;
- denial of choice, self-determination and citizenship rights (e.g. around food, expressions of sexuality, lifestyle);

- failure to help get an early diagnosis of dementia because of the social stigma and fear attached to it;
- weaknesses and failures in medical treatments (e.g. inappropriate use of neuroleptic drugs), poor health and social care systems – statutory and voluntary;
- failure by some services to support the needs of family and other informal carers of people with dementia;
- stigmatising and degrading images and representations of people with dementia in the media and wider culture (newspapers, film, television, theatre, art, literature etc);
- inadequate or absent state legislation and official policies in the interests of people with dementia.

It is a hallmark stance of disability studies and disability rights politics that disabled people must have every opportunity to be self-determining (Campbell and Oliver, 1996). This means that their voices, however expressed, must be heard and facilitated. The empowerment and involvement of people living with dementia in their own life circumstances and choices should be paramount, and advocacy should respect this starting point. It follows that despite the many challenges presented by dementia and its impairment effects, non-disabled people need to find innovative and imaginative ways to make rights a reality for people with dementia (see for example Mental Health Foundation, 2015).

Adding theoretical weight to the social model perspective

Applying the social model of disability to living with dementia has certainly been an innovative and informative move, but there are inevitably limitations because the social model is not a theory of disability. Mike Oliver and other leading social modellists have made this point repeatedly: the social model of disability is only a model:

> … *the social model of disability is… not a substitute for social theory, a materialist history of disability nor an explanation of the welfare state (Oliver, 1996, pp. 41).*

Vic Finkelstein (2001, pp. 6) has added, with regret: 'Sadly a lot of people have come to think of the social model of disability as if it were an explanation, definition or theory, and many people use the model in a rather sterile formalistic way'. So, while the social model of disability serves as a powerful banner headline

for campaigns, as a strong organising principle for disability politics, and as an effective framework for identifying social barriers, it does not theorise disability. Another way of putting this is that the social model is an effective starting point but lacks explanatory power: we need to be able to explain why social barriers come into existence in the lives of people who have types of impairment – including dementia.

In essence, the key theoretical question is as follows: Why is it that the social relationship between people with and without impairments is one that involves the social oppression of the former by the latter? This is a very difficult question to answer – as are the parallel questions in older branches of equality and diversity studies: why does sexism exist? why racism? why homophobia? These observations suggest that the study of dementia and disability necessitate paying attention to some of the theoretical work underway within disability studies. At this point, it is useful to introduce and define the concept *disablism* – because this attempts to capture the social relationship that underpins social barriers:

> **Disablism**: *refers to the social imposition of avoidable restrictions on the life activities, aspirations and psycho-emotional well-being of people categorised as 'impaired' by those deemed 'normal'. Disablism is social-relational in character and constitutes a form of social oppression in contemporary society – alongside sexism, racism, ageism, and homophobia. As well as being enacted in person-to-person interactions, disablism may manifest itself in institutionalised and other socio-structural forms. (Thomas 2010, pp. 37).*

Explaining disabling barriers: theoretical perspectives

Writers and researchers in disability studies have turned to a variety of social theories to find answers to questions about the existence of disablism. As in any other field, different theoretical perspectives have provided contrasting explanations of disablism. In summary, the two overarching theoretical frameworks in use in disability studies are as follows (see Thomas, 2007):

Theories based on principles in philosophical realism (or materialism)
These include ideas advanced by key members of UPIAS and the work of subsequent writers who usually characterise themselves as belonging to one of the following traditions: Marxists, materialists, critical realists, feminist materialists (not an exclusive list).

Building on the ideas of disability activists, materialist scholars have theorised disability and disablism as outcomes of the way fundamental activities are organised in society – especially, but not exclusively, activities in the economic domain in the industrial era. In their view, the roots of the social marginalisation and spatial segregation of people with impairments are located in the historical development of capitalist commodity production and exchange. These socio-economic developments gave rise to social relationships between 'the normal' and 'the impaired' that systematically disadvantaged and disempowered the latter. The foundations were laid for medicalised systems of 'treatment and care' that subjected disabled people to professional control and enforced dependency, first in institutional regimes and later in systems of 'community care'. These perspectives have also unleashed a great deal of research detailing the social exclusion of disabled people in all social arenas in the contemporary era. Materialists have been sensitive, however, to the charge that their approach ignores or attaches insufficient significance to the role that cultural practices and processes play in shaping disablism. Their response has been to insist that attitudes, discourses and ideological representations are critical to disablism, though there is an insistence that these are materialised through the social practices required to meet basic needs. (Thomas, 2007, pp. 81).

Theories based on ideas about phenomena (idealism)
These perspectives came to prominence in disability studies later (1980s onward) – following what is known as the *cultural turn* in the social sciences more generally. The ideas of the social philosopher Foucault have been particularly influential (see Corker and Shakespeare, 2002; Tremain, 2005). Writers in this broad theoretical tradition usually characterise themselves as one of the following: poststructuralists, postmodernists, feminist postmodernists, queer theorists, anti-foundationalists (not an exclusive list):

[These writers] have found poststructuralist theoretical perspectives, particularly Foucauldian and feminist variants, to be of [great] interest and utility. The cultural, the discursive, and the linguistic have assumed pre-eminence in poststructuralist theorisations of disability and impairment. Materialist perspectives are dismissed as modernist grand narratives – systems of thought imbued with conceptual dualisms: abnormal/ normal, disabled/non-disabled. The deconstruction of such [dualist] thinking comes to the forefront. Many faults are found with the social model of disability – the offspring of the UPIAS materialist interpretation of disability, with a key failing purported to reside in the model's impairment/disability distinction. This, it is argued, merely

replicates the problematic modernist biology/society dualism. Poststructuralists have interrogated the category 'impairment', and set about exposing what they see as its entirely socially constructed character. (Thomas, 2007, pp. 81).

If we apply these two theoretical perspectives to the relationship between people with dementia and so-called 'normal' members of society (i.e. between the disabled and non-disabled), we arrive at contrasting explanations of the disablism and social barriers that have come into existence in the lives of people with dementia. In essence:

- *Materialist perspectives* would highlight the way that capitalist economies have no use for the cognitively impaired, especially if they are old. This is because criteria of being socially valued are closely tied up with being able to work for wages/salaries (now or in the future) — particularly being able to fit into economic roles that generate profit. People who cannot work are therefore (in crude terms): excluded from the mainstream; warehoused; kept alive using minimal social resources; placed under the 'legitimate' control of doctors and 'carers'; kept out of the way of essential social activities etc. The category 'older people with dementia' combines two disadvantaged groups in capitalist economies — the cognitively impaired and the old. This means that old people with dementia are especially vulnerable to disablism.

- *Poststructuralist perspectives* would highlight the cultural meanings that attach to particular body types and behaviours. The bodies and behaviours of people with dementia carry negative cultural meanings in our society — a society that values youth, beauty and celebrity. The negative meanings associated with having dementia, especially in its middle and late stages, include 'abnormal', 'undesirable', and 'weird' — even 'disgusting'. These cultural meanings stem from systems of knowledge ('discourses') that come to have authority in society. Such authoritative systems of knowledge are those that are specialist and influential, and these in turn give social power to those that possess the knowledge: knowledge is power. In recent centuries, the institutions and groups that have maintained or acquired social power via their specialist knowledge include: dominant establishment faiths and churches, judiciary, state officials, scientists, and doctors. In matters of impairment and disease, it is members of the medical profession who hold power; their specialist scientific knowledge about dementia and other conditions allows them to define and treat abnormalities of body and mind, and to oversee regimens of treatment and 'care'. Medical ideas are then able to shape thinking in other cultural institutions (e.g. the media) and inform knowledge in the wider society. In

this way, everyone starts to share and elaborate ideas about what it means to be 'demented' 'mentally abnormal', 'mad', and 'dangerous'. Such cultural ideas seem to justify shutting people up in institutions, controlling 'difficult behaviours' through medical or pharmaceutical solutions and ignoring what they say. In addition, studies by poststructuralists are particularly interested in the genealogy (the historical development) of key ideas and categories — for example, the category 'dementia' in the medical lexicon.

If we look again at the social barriers listed above, we can see that explanations for the existence of these barriers will vary considerably depending on which theoretical stance one starts from. Perhaps of greater significance for this paper are the consequences that follow if one thinks through '*how can we dismantle the barriers?*'

- *The materialist theoretical stance* suggests that changes need to begin in the economic realm. Changes will then follow on in other societal domains.
- *The postmodernist stance* suggests that changes need to begin in the cultural realm — that is, in the realm of ideas and knowledge. Changes are then likely to follow on in other societal domains.

Intersectionality and psycho-emotional disablism

In this section we consider two concepts that have become important in theoretical work and political thinking in disability studies today. These concepts are intersectionality and psycho-emotional disablism, and are introduced here because they are particularly helpful in thinking through the social features of living with dementia.

Intersectionality and 'difference'
Intersectionality is a term originally developed by feminist theorists in their attempt to understand the consequences of the overlapping fragments of our identities: our gender, ethnicity, sexuality, age and social class (see McCall, 2005; Walby *et al.*, 2012; Bilge, 2010). These many fragments remind us not to homogenise categories, such as: 'the disabled' or 'the old'. Matters of social diversity and multiple inequality come to the fore when we look at individuals' biographies and how their characteristics interact to shape life chances and capacities to resist disadvantage and social oppression. In disability studies, some researchers have used the concept of intersectionality to look at how disablism, in its many forms of expression, can have a differential impact on people depending

on their simultaneous vulnerability to sexism, ageism, racism and homophobia (Bê, 2012; Stienstra, 2012). For example, it you have middle stage dementia and are female, old and 'poor' you may be more vulnerable to aspects of disablism *and* other faces of oppression (sexism, ageism etc) than if you have middle stage dementia but are male, under 65 years old and from a professional background. Some more affluent people, and their families, are more likely to have access to resources that can protect a person with dementia from some of the social barriers listed above. There is nothing certain or automatic about this for individuals, but there will be social patterns associated with intersectionality that connect with degrees of vulnerability to disablist social barriers at early, middle and late stages of dementia.

The interaction of disablism and ageism is obviously of particular importance in this paper. For example, the impairment effects in early stage dementia are commonly short-term memory loss and difficulty making decisions but these can often be attributed to 'just being old' in a society imbued with ageist attitudes. For many people with dementia there is a twofold discrimination underway – one of ageism and one of disablist stigma attached to behaviours that appear to signal mental illness. An older person is often stereotyped and reduced to an ageing body that is devoid of sex, gender, class, cultural knowledge etc., and this can be reinforced by staff practices and the interior design and layout of institutions such as hospitals and residential care settings. How many care homes have double rooms to enable a husband and wife to live together? Are same-sex couples even on the radar? Further, with the exception of the very few faith-based care homes in the UK, cultural needs are largely ignored because the focus is on *body care*. For those with dementia – who are often less able to vocalise their preferences, needs and desires – *others* often fail to consider the former's person-centred needs, and think they have the right to make decisions on *behalf* of the person with dementia. Gilleard *et al.*, (2005) argue however that taking a social model of disability approach to dementia means that those around people with dementia can review the impact that they, as 'non-demented' people, can have on others; can reconsider the value of hearing and responding to personal experience and can focus on abilities rather than losses.

Psycho-emotional disablism

Another useful theoretical concept for understanding *some* of the social barriers that confront people with dementia is psycho-emotional disablism (Thomas, 1999). This concerns the intended or unintended hurtful words, behaviours and social actions of non-disabled people in inter-personal engagements with people

with dementia. There are several examples of psycho-emotional disablism listed as social barriers above; one example is: lack of sympathy and tolerance on the part of some non-disabled people.

The presence of psycho-emotional disablism means that in addition to coping with the impairment effects that dementia brings, people living with the condition have to put up with the insults and emotional damage inflicted by non-disabled people. Put another way, this is a form of disablism that works along psychological and emotional pathways. This psycho-emotional disablism can impact negatively on self-esteem, personal confidence, and sense of security. Indeed, disabled people can be made to feel worthless, useless, of lesser value, ugly and burdensome (Thomas, 1999; Reeve, 2002, 2006). In this way, psycho-emotional disablism places further limits on who people can be by shaping individuals' 'inner worlds', sense of 'self', and social behaviours. Moreover, impairments may themselves be affected in problematic ways by the impact of psycho-emotional disablism. For example, a mother whose early stage dementia causes her to be forgetful may have this trait worsened by an adult son who displays his frustration and keeps on complaining about his mother's loss of memory.

Services and spaces/places

There is currently a great deal of public interest in dementia in the UK – as the so-called burden of the costs of caring for an ageing population with 'high support needs' occupies the minds of politicians and policy-makers (see, for example, The Prime Ministers Challenge on Dementia (DoH, 2012); the Alzheimer's Society Report, 2014; National Audit Office, 2010; Quality Outcomes for People with Dementia: Building on the work of the National Dementia Strategy, 2010). We do not have the space here to critically review the reports on services and strategy published in recent years, but it is informative and telling to look at one authoritative document published in 2012: the World Health Organization's report *Dementia: A Public Health Priority*. This global report, one that is likely to have an impact on governments and policy-makers internationally, flags up the patterns of ageing across the world – in both wealthy and low-income countries:

> *Prevalence and incidence projections indicate that the number of people with dementia will continue to grow, particularly among the oldest old, and countries in demographic transition will experience the greatest growth. The total number of people with dementia worldwide in 2010 is estimated at 35.6*

million and is projected to nearly double every 20 years, to 65.7 million in 2030 and 115.4 million in 2050. The total number of new cases of dementia each year worldwide is nearly 7.7 million, implying one new case every four seconds. (WHO 2012: 2)

It is worthy of note that this report makes only passing reference to recognising the rights of people with dementia, and of working to maintain their independence, dignity, identity and personhood. Rather, the report frames dementia – and by implication those living with dementia – as a social, economic and health burden on society. Passing reference is certainly made to addressing widespread fear of dementia, to the stigma attached to dementia, and to the need to develop a 'dementia friendly society' – but there is little said about how this might be actively achieved. Hope is raised when reference is made to the relevance of the United Nations Convention on the Rights of People with Disabilities (CRPD, 2006) but, overall, the report takes a medicalised approach to dementia that is couched in terms of disease burden, treatment, risk, service provision and the needs of carers. From a disability rights perspective, the report leaves the reader with a disappointing sense of *déjà vu*.

Dementia and place B head
As noted above, adapting the social model of disability and anti-disablist thinking to people with dementia requires us to think not just about the social and institutional disadvantage that those with dementia can experience, but also about the ways in which this is played out through the everyday places they inhabit. Those with dementia can lose a sense of time and space, making formerly familiar places unfamiliar and frightening, for example wandering through known streets at night. A standard institutionalised response to these impairment effects is to view these as 'risky behaviours' , the 'treatment' for which is confinement to the home or a residential setting unless accompanied by a 'responsible adult'. Of course, it would be dangerous to place vulnerable people in potentially harmful situations, but an anti-discriminatory perspective points instead to the need to develop accepting communities (Dunn, 1999; Beresford *et al.*, 2011). This challenge has more recently been taken up through a focus on the development of the Dementia Friendly Communities programme – spearheaded by the Alzheimer's Society and the Joseph Rowntree Foundation in 2012. This initiative is designed to work collaboratively with people affected by dementia and key partners to improve inclusion and quality of life for those living with dementia. A key vision of this strategy is that it will support the development of enabling environments, so people within these communities will better understand and be

supportive of people with dementia; enhancing inclusion and enabling people with dementia to maintain greater independence and have greater choice and control over their lives.

This approach was originally developed to counter the exclusion of people stigmatised by poor mental health. For Dunn, this not only required a greater understanding of the relationship between the individual and the wider community, but also insisted that we look at how society judges the value of individuals and responds to mental ill-health. It requires asking how 'risk' should be defined, and what is meant and understood by the participation and the empowerment of individuals within a community. Understanding and valuing differences can only be resolved through the engagement of all involved. With regard to dementia, these practices would be based not just on a wider understanding of the changing behaviour patterns that occur with dementia but on developing caring communities that are supportive and accepting of social difference. For example, knowing that 'Mrs Smith' has dementia and may be confused about time and space means that we recognise the challenges she faces and watch out for her, rather than viewing her behaviour as deviant and her family as somehow failing in their duty to care. Moreover, it means working out ways of helping her to avoid potential dangers, or recognising that she may need support getting to where she wants to go.

Developments in technology – such as personalised tracking devices – may enable people with dementia and their carers to identify 'safe spaces' within the community. A feeling of safety in space/place allows a person with dementia to move around comfortably, enabling them to retain a sense of independence that may otherwise be denied (Milligan, 2009). Critically, however, these technologies rely on local networks of support to be effective (Roberts *et al.*, 2012). In other words, they rely on having local family or members of the community who are willing and able to respond when an alarm is triggered; that is, an accepting community is one that recognises the challenges and is willing to support this kind of innovation.

Where care and support for people with dementia takes place, and the nature of those places, is important. The short-term memory loss associated with dementia means that new and unfamiliar places can add to the confusion already experienced by an individual with dementia. Supporting those with dementia to stay within their own homes for as long as possible is key to helping them to maintain a sense of self and identity. The presence of familiar objects within the

home – private possessions, photographs and so on – represents what Augè (1995) referred to as 'anthropological space', where the long-term memory provides a sense of safety; familiar visual cues can help the individual with dementia to more successfully negotiate that space, so extending their ability to self-help (Milligan, 2003). As a visual manifestation of a person's identity and personhood, the home places limits on the extent to which an individual can be objectified and depersonalised – something that often happens in collective institutional settings.

Conclusion

We hope to have shown that applying the social model of disability to living with dementia results in some important insights and observations. Light is also thrown on the way that disablism overlaps with ageism in society, and on how space and place acquire special relevance. Attention has also been drawn to the necessity of uncovering the theoretical perspectives that help to *explain* the *social barriers* that the social model of disability highlights in the lives of people with dementia. This, in turn, has directed the focus toward useful concepts such as intersectionality and psycho-emotional disablism. This Viewpoint paper sets out approaches to dementia that are at odds with conventional thinking in official and medical circles. We hope that this will stimulate debate about new ways forward in both understanding and meeting the needs of the growing number of people living with dementia.

Acknowledgements

Notes

1   The Work Health Organization (WHO) defines impairments as: significant deviations or loss of body functions and body structures (including psychological function). This is part of the WHO's *International Classification of Functioning, Disability and Health (ICF)* See: www.who.int/classifications/icf/en/. Refer to note 4 below on the concept 'impairment effects'.

2   Disability Studies is the academic wing of the Disabled People's Movement in the UK. This academic discipline now has a strong presence in the university sector across the globe.

3   In terms of impairment, the definition of dementia in use here is as follows, from the WHO Report on Dementia (WHO, 2012, pp. 7). 'Dementia is a syndrome due to disease of the brain – usually of a chronic or progressive nature – in which there is disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgement. Consciousness is not clouded. The impairments of cognitive function are commonly accompanied, and occasionally preceded, by deterioration in emotional control, social behaviour, or motivation. This syndrome occurs in a large number of conditions primarily or secondarily affecting the brain. Alzheimer's disease is the most common form of dementia and possibly contributes to 60–70 per cent of cases. Other major contributors include vascular dementia, dementia with Lewy bodies, and a group of diseases that contribute to frontotemporal dementia. The boundaries between subtypes are indistinct and mixed forms often co-exist. Dementia affects each person in a different way, depending upon the impact of the disease and the person's pre-morbid personality. The problems linked to dementia can be understood in three stages:

   • early stage – first year or two; middle stage – second to fourth or fifth years; late stage – fifth year and after. These periods are given as an approximate guideline only – sometimes people may deteriorate more quickly, sometimes more slowly. It should be noted that not all persons with dementia will display all the symptoms.

4   Carol Thomas (1999) introduced the concept *impairment* effects in Disability Studies –
    now widely used in the discipline – defined as follows: '*Impairment effects*: the direct and
    unavoidable impacts that "impairments" (physical, sensory, intellectual, emotional) have
    on an individual's embodied functioning in the social world. Impairments and impairment
    effects are always bio-social and culturally constructed in character, and may occur at
    any stage in the life course.' (Thomas, 2010, pp. 37). It is important that impairment
    effects are not mistaken for the restrictions and limitations in individuals' lives that
    are actually caused by disablism. The WHO Report on Dementia usefully sets out the
    impairment effects associated with dementia in a 'common symptoms' table (WHO,
    2012, pp. 7).

References

Alzheimer's Society (2014) *Dementia 2014: opportunity for change*. London: Alzheimer's Society. Available at: www.alzheimers.org.uk/site/scripts/download_info.php?fileID=2317 (accessed on 6 February 2015)

Augè, M. (1995) *Non-places: introduction to an anthropology of supermodernity*. London: Verso

Barnes, C. (2012) 'Understanding the social model of disability: past, present and future', in Watson, N., Roulestone, A. and Thomas, C. (eds) *Routledge handbook of disability studies*. London: Routledge, pp. 12 –29

Beattie, A., Daker-White, G., Gilliard, J. and Means, R. (2005) '"They don't quite fit the way we organise our services"—results from a UK field study of marginalised groups and dementia care', *Disability & Society*, Vol. 20, No 1, pp. 67–80

Bê, A. (2012) 'Feminism and disability: a cartography of multiplicity', in Watson, N., Roulestone, A. and Thomas, C. (eds) *Routledge handbook of disability studies*. London: Routledge, pp. 363–375

Beresford, P. (2002) 'Thinking about "Mental Health": towards a social model', *Journal of Mental Health*, Vol.11, No.6, pp. 581–4

Beresford, P., Fleming, J., Glynn, M., Bewley, C., Croft, S., Branfield, F., and Postle, K. (2011) *Supporting people: towards a person-centred approach*. Bristol: The Policy Press

Bilge, S. (2010) 'Recent feminist outlooks on intersectionality', *Diogenes*, Vol. 57, No. 1, pp. 58–72

Blackman, T.I.M., Mitchell, L., Burton, E., Jenks, M., Parsons, M., Raman, S. and Williams, K. (2003) 'The accessibility of public spaces for people with dementia: a new priority for the 'open city', *Disability & Society*, Vol. 18, No.3, pp. 357–371

Boyle, G. (2014) 'Recognising the agency of people with dementia', Disability & Society, Vol. 29, No.7, pp. 1130–1144

Brittain, K., Corner, L., Robinson, L. and Bond, J. (2010) 'Ageing in place and technologies of place: the lived experience of people with dementia in changing social, physical and technological environments, *Sociology of Health & Illness*, Vol. 32, No.2, pp. 272–287

Cabinet Office (2004) *Improving the life chances of disabled people.* London: The Prime Minister's Strategy Unit

Campbell, J. and Oliver, M. (1996) *Disability politics: understanding our past, changing our future.* London: Routledge

Corker, M., and Shakespeare, T. (eds) (2002) *Disability/postmodernity: Embodying disability theory.* London: Continuum

Davis, S., Byers, S., Nay, R. and Koch, S. (2009) 'Guiding design of dementia friendly environments in residential care settings: Considering the living experiences', *Dementia,* Vol. 8, No. 2, pp.185–203

Department of Health (2012) *Prime Minister's challenge on dementia. Delivering major improvements in dementia care and research by 2015.* London: Department of Health

Dorenlot, P. (2005) 'Editorial', *Dementia,* Vol. 4, No.4, pp. 459–461

Dunn. S. (1999) *Creating accepting communities.* London: MIND Publications

Finkelstein, V. (2001) 'A personal journey into disability politics'. The Disability Studies Archive UK, Centre for Disability Studies, University of Leeds. Available at www.independentliving.org/docs3/finkelstein01a.pdf (accessed on 12 May 2015)

Gilleard, G., Means, R., Beattie, A. and Daker-White, G. (2005) 'Dementia care in England and the social model of disability – lessons and issues', *Dementia,* Vol. 4, No. 4, pp. 571–586

Kitwood, T. (1997) *Dementia reconsidered: the person comes first.* Buckingham: Open University Press

McCall, L. (2005) 'The complexity of intersectionality, *Signs', Journal of Women in Culture and Society,* Vol. 30, No. 3, pp. 1771–800

Mental Health Foundation (2015) *Dementia, rights, and the social model of disability: a new direction for policy and practice?* London: Mental Health Foundation

Milligan, C. (2009) *There's no place like home: people, place and care in an ageing society.* Aldershot: Ashgate

Milligan, C. (2003) 'Location or dis-location: from community to long term care – the caring experience', *Journal of Social and Cultural Geography,* Vol. 4, No.4, pp. 455–470

National Audit Office (2010) Improving dementia services in England – an interim report. Available at: www.nao.org.uk/publications/0910/improving_dementia_services.aspx (accessed on 12 April 2012)

Oliver, M. (2004) 'The social model in action: if I had a hammer, in Barnes, C. and Mercer, G. (eds) *Implementing the social model of disability: theory and research*. Leeds: The Disability Press

Oliver, M. (1996) *Understanding disability: from theory to practice*. London, Macmillan

Oliver, M. (1983) *Social work with disabled people*. Basingstoke: Palgrave Macmillan

Pearson, C. (2012) 'Independent living', in Watson, N., Roulestone, A. and Thomas, C. (eds) *Routledge handbook of disability studies*. London: Routledge, pp. 240–252

Priestley, M. (2003) *Disability: a life course approach*. Cambridge: Polity

Proctor, G. (2001) 'Listening to older women with dementia', *Disability & Society*, Vol. 16, No.3, pp. 361–376

Quality Outcomes for People with Dementia: Building on the work of the National Dementia Strategy (2010). Available at: www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_119827   (accessed on 12 April 2012)

Reeve, D. (2006) 'Towards a psychology of disability: the emotional effects of living in a disabling society' in Goodley, D. and Lawthom, R. (eds) *Disability and psychology: critical introductions and reflections*. Basingstoke: Palgrave Macmillan

Reeve, D. (2002) 'Negotiating psycho-emotional dimensions of disability and their influence on identity constructions', *Disability & Society*, Vol. 17, No. 5, pp. 493–508

Roberts, C., Mort, M. and Milligan, C. (2012) 'Calling for care: 'disembodied' work, teleoperators and older people living at home', *Sociology*, Vol. 46, No. 3, pp. 490–506

Stienestra, D. (2012) 'Race/ethnicity and disability studies: towards an explicitly intersectional approach', in Watson, N., Roulestone, A. and Thomas, C. (eds) Routledge *Handbook of Disabiliy Studies*. London: Routledge

Thomas, C. (2010) 'Medical sociology and disability theory', in Scambler G. and Scambler , S. (eds) *New directions in the sociology of chronic and disabling conditions: assaults on the lifeworld*. Basingstoke: Palgrave Macmillan, pp. 37–56

Thomas, C. (2007) *Sociologies of disability and illness. contested ideas in disability studies and medical sociology.* Basingstoke: Palgrave Macmillan

Thomas, C. (1999) *Female forms: experiencing and understanding disability.* Buckingham: Open University Press

Tremain, S. (2005) *Foucault and the government of disability.* Michigan: The University of Michigan Press

Union of the Physically Impaired Against Segregation (UPIAS) (1976) *Fundamental principles of disability.* London: UPIAS

United Nations Convention on the Rights of People with Disabilities (CRPD) (2006) Available at: www.un.org/disabilities/default.asp?navid=14&pid=150. (accessed on 6 March 2012)

Walby, S., Armstrong, J. and Strid, S. (2012) 'Intersectionality: multiple inequalities in social theory', *Sociology*, Vol. 46, No. 2, pp. 224–4

Walmsley, J. (1991) '"Talking to the top people": some issues relating to the citizenship of people with learning difficulties', *Disability, Handicap and Society,* Vol.6, No.3, pp. 219–31

WHO and Alzheimer's Disease International (2012) *Dementia: a public health priority.* Geneva: World Health Organization

About this paper

This Viewpoint paper was written by Carol Thomas and Christine Milligan, as a contribution to JRF's programme Dementia Without Walls. Carol and Christine are colleagues in the Division for Health Research, Faculty of Health and Medicine, at Lancaster University. Carol Thomas is Professor of Sociology, and Director of the Centre for Disability Research (CeDR). Christine Milligan is Professor of Health and Social Geography, and Director of the Lancaster University Centre for Ageing Research (C4AR).

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