Dementia and the social model of disability: does responsibility to adjust lie with society rather than people with dementia?

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In the Winter 2015-16 volume of this journal, Philly Hare set out the Joseph Rowntree Foundation's (JRF) vision for a future in which the UK became a good place for people with a diagnosis of dementia to live. In her words, the JRF wanted to, "ensure that people living with dementia are more understood, more heard, more included, more connected and more supported" (p. 9). Part of the drive toward this goal was to think about how we might change society's thinking and attitudes toward dementia and what an inclusive UK society in the context of dementia actually means. One outcome of this goal was the commissioning of a 'think piece' by the authors of this article about how we might draw on the well-established social model of disability to develop this thinking (REF). We discuss the key elements of this think-piece in this article, but it is worth noting that this was paralleled by companion paper written by Toby Williamson (Mental Health Foundation, 2015), designed to encourage new thinking and debate about dementia as a human rights issue.

What is the social model of disability?

Before applying the social model of disability to dementia, we need to look at what this model is, and where it has come from. The social model of disability was first coined by the disabled activist and writer, Mike Oliver in the early 1980s in his attempt to capture novel ideas about disability, developed by disabled people themselves in the previous decade (Oliver, 1983). At its core was the view that disabled people were socially disadvantaged - not so much by their impairments - but by the negative responses of those deemed to be non-disabled. Oliver and his contemporaries thus drew attention to a form of social relationship between disabled and non-disabled people predicated on social inequality. This relationship makes its presence felt in a number of ways: in interactions between individuals; through rules and practices in social institutions (such as schools and hospitals); and in the disabling structure of the physical environment including buildings, systems of travel and so forth. This perspective contrasted markedly with the dominant biomedical view of the time: that being impaired is an abnormality that causes major problems and limitations in the lives of 'the disabled'. It also takes issue with assumptions that disabled people should be pitied because it is their damaged bodies and minds that stop them participating in 'normal' activities.

Instead, the social model of disability drew attention to the social and physical barriers erected by non-disabled people in all social arenas and captured the idea that people with physical impairments are a socially oppressed group in modern societies. Before long, those with impairments beyond the straightforwardly physical began to question their apparent exclusion from this initial formulation of the model. In the 1980s and 1990s, the case was made – and won – that people who live with sensory or intellectual/cognitive impairments (principally learning difficulty) are also disabled people in that they too experience similar forms of exclusion and social barriers (Barnes, 2012). Who counts as disabled was further widened in the 1990s and 2000s to include people with chronic illnesses and mental health problems (e.g. Walmsley, 1991; Beresford, 2002). Hence, the social model of disability can be seen to apply to a growing proportion of the population with lifelong, acquired or attributed impairments. In 2004, Oliver clarified his original thinking, stating:

> *…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 p.21).*

Because of its conceptual simplicity, the social model of disability became a banner headline for the Disabled People's Movement in the UK. Indeed, from the 1980s onwards, it has proven an extremely effective tool in campaigns for disability rights (Campbell and Oliver, 1996). Legislative achievements of particular note include 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 of financial arrangements designed to facilitate independent living in the 1990s – 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), which laid innovative conceptual foundations for the 2010 Equality Act and the follow-up Equality Duty, now in force in England, Scotland and Wales.

Given this background and history, it is unsurprising that a small, but growing, number of researchers and activists should begin to think about how the social model of disability might also apply to people with dementia. Here, the impairments and impairment effects associated with dementia are viewed as foundations upon which social barriers are erected by non-disabled people – whether purposively, or from lack of understanding and knowledge. Adopting the social model of disability has encouraged researchers to look more closely at the everyday experiences and perspectives of people with dementia (Proctor, 2001; Blackman *et al*., 2003; Dorenlot, 2005; Beattie *et al*., 2005; Davis *et al*., 2009; Brittain *et al*., 2010; Boyle, 2014). What is disappointing, however, is not only the relatively small number of researchers that have taken this approach, but the peripheral nature of their work within disability studies. The latter perhaps arises from two weaknesses of note in disability studies in the last 40 years: firstly, the tendency to ignore or sideline older people and their particular social interests (Priestley, 2003); and secondly, the failure to understand and take account of the needs and interests of younger people (under 65 years old) with dementia. This has been compounded by the tendency of many gerontologists, psychologists and social scientists to view dementia through a largely biomedical lens until relatively recently.

There are however a few key researchers who have adopted more radical perspectives that have been influential in shaping our thinking about dementia. Tom Kitwood's (1997) ideas about personhood, for example, insist that we look at, and recognize, '*the person* with dementia' and not focus on 'the person with dementia'. This[2] 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 things and on what they can and cannot do, the individual is not *defined* by having dementia. In other words, Kitwood's concept of personhood reminds us that people with dementia are still thinking and feeling individuals, who have different identities, personal histories, experiences, likes and dislikes. This emphasizes the need to respect, value and celebrate what individuals *can* do rather than define them by their dementia; doing the latter simply reinforces the medicalization of that individual, relegating them to 'demented body' status.

Those commentators who *have* applied the social model of disability to dementia have identified both the presence and operation of social barriers in the lives of people living with dementia (e.g. Blackman *et al*., 2003; Dorenlot, 2005; Beattie *et al*., 2005; Davis *et al*., 2009; Brittain *et al*., 2010). There are many different forms of dementia with impairment effects that manifest in different ways for different people. This means that, especially in the early, middle or late stages of dementia, the social barriers in evidence vary in the profundity of their disabling consequences. Put another way, impairment effects and disablism interact, with differential outcomes.

In Table 1 we set out some examples of social barriers that can be experienced by people with dementia, whilst in Table 2 we provide examples of barriers that can become embedded in institutional and collective practices:

Table 1: Individual attitudinal and behavioural barriers

- lack of understanding of the impairment effects that come with the stages of dementia on the part of 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';
- treating people with dementia as passive and dependent. Failing to ask what they want, how they feel, what would help to improve things in their lives etc.
- 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.

Table 2: 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
- 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.
- food, expressions of sexuality, lifestyle.

A further hallmark of the social model of disability is that that disabled people should have every opportunity to be self-determining (Campbell and Oliver, 1996). This means that their voices, however expressed, should be heard and facilitated. The empowerment and involvement of people living with dementia in determining 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 dementia has certainly been an innovative and informative move, but there are inevitable limitations, because the social model is not a *theory* of disability. Mike Oliver and other leading proponents of the social model (e.g. Finkelstein, 2001) have made this point repeatedly. So, while the social model of disability serves as a powerful banner headline for campaigns and as an effective framework for identifying social barriers, it does not theorise disability. So whilst it is an effective starting point, it lacks the explanatory power of theory. That is, 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.

Disablism

In essence, then, the key question is: 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 require us to pay attention to some of the theoretical work underway within disability studies. At this point, it is perhaps useful to introduce and define the concept of *disablism* – because this attempts to capture the social relationship that underpins social barriers. Following Thomas (2010, p.37) 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... As well as being enacted in person-to-person interactions, disablism may manifest itself in institutionalised and other socio-structural forms.*

The interaction of disablism and ageism is of particular relevance to our discussion. For example, impairment effects in early stage dementia often include short-term memory loss and difficulty making decisions, but these can also 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 may be less able to vocalise their preferences, needs and desires, *others* often make decisions on behalf of the person with dementia. In doing so, they often fail to consider the former's person-centred needs. Gilleard *et al*., (2005) however, maintain that taking a social model approach to dementia means that those around people with dementia should review the impact that they, as 'non-demented' people, have on others; reconsider the value of hearing and responding to personal experience; and focus on abilities rather than losses.

Insights from Materialism and postructuralism

Writers and researchers in the disability field have turned to a variety of social theories to try to find answers to questions about the existence of disablism. As in any other field, different theoretical perspectives provide contrasting explanations of disablism. We summarise the two overarching theoretical frameworks in use in disability studies below:

1) Materialist scholars theorise disability and disablism as outcomes of the way basic activities are organised in society – especially, but not exclusively, economic activities. Here, the roots of social marginalisation and spatial segregation of people with impairments are viewed as being located in the historical development of capitalist production and exchange. These developments gave rise to social relationships between 'the normal' and 'the impaired' that systematically disadvantaged and disempowered the latter. This laid the foundations 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 lead to a great deal of research around the social exclusion of disabled people in all social arenas in the contemporary era.

2) Theories based on ideas about phenomena (idealism) came to prominence in disability studies following what is known as the cultural turn in the social sciences in the 1980s more generally. The ideas of the social philosopher Foucault and feminist variants have been particularly influential (see Corker and Shakespeare, 2002; Tremain, 2005). Here, the cultural, the discursive, and the linguistic have assumed pre-eminence in poststructuralist theorisations of disability and impairment. Materialist perspectives are dismissed as modernist systems of thought that are infused with conceptual dualisms: abnormal/normal, disabled/non- disabled. Unpicking this type of dualist thinking comes to the forefront. Many critiques of the social model of disability are raised, with a key critique focusing on what commentators see as the model's impairment/disability distinction. This, they argue, merely replicates the problematic biology/society dualism. Poststructuralists have interrogated the category 'impairment', and set about exposing what they see as its entirely socially constructed character.

If we apply these two key theoretical perspectives to the relationship between people with dementia and non-demented members of society (i.e. between the disabled and non-disabled), we arrive at contrasting explanations of the disabling and social barriers that exist in the lives of people with dementia.

In sum, materialist perspectives would highlight how capitalist economies have no use for the cognitively impaired, especially if they are old. This is because social value is closely tied to the ability 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. From this perspective, the category 'older people with dementia' is seen to combine 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, however, 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', 'bizarre' – and even 'disgusting'. These cultural meanings stem from systems of knowledge ('discourses') that become authoritative 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. 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 the medical profession. In matters of impairment and disease, it is members of the latter group 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 then shape thinking in other cultural institutions (e.g. the media) and inform knowledge in the wider society. As a consequence, everyone starts to share and elaborate ideas about what it means to be ‘demented’ ‘mentally abnormal’, ‘mad’, and ‘a danger to themselves and others’. The proliferation of these stereotypes acts to justify institutionalizing people, controlling ‘difficult behaviours’ through medical or pharmaceutical solutions and ignoring what those with dementia say.

So if we look again at the social barriers discussed above, we can see that explanations for the existence of these barriers vary, depending on the theoretical stance taken. Perhaps of greater significance for this article are the consequences that follow if we begin to think through how we might dismantle the barriers. From a materialist stance, change would need to begin in the economic realm. Transformations would then follow in other societal domains. From a post-structural perspective, however, change needs to begin in the cultural realm, i.e. in the realm of ideas and knowledge. Changes are then likely to follow on in other societal domains.

Dementia, intersectionality and psycho-emotional disablism

Two further concepts, intersectionality and psycho-emotional disablism, are worth discussing in relation to contemporary thinking within disability studies. We introduce these ideas because they are particularly helpful in thinking through the social features of living with dementia.

Intersectionality highlights the overlapping parts of our identities, for example, gender, ethnicity, sexuality, age and social class (e.g. Stienestra, 2012; Walby et al, 2012). This is important because it reminds us that people are not homogenous and cannot simply be grouped together by a single characteristic, such as disability or age. When looking at individuals’ biographies, it is important to take account of how issues of social and cultural diversity, multiple inequality and other characteristics interact to shape people’s life chances and capacities to resist disadvantage and social oppression. 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. Those from more affluent backgrounds are more likely to have access to resources that can protect a person with dementia from some of the social barriers listed above. While there is nothing certain or automatic about this at the level of the individual, 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.

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Psycho-emotional disablism

Another useful theoretical concept for helping us to understand *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 or practices of non-disabled people in their inter-personal engagements with people with dementia. There are several examples of psycho-emotional disablism listed in Table 1 above; one example relates to 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 may have to put up with insulting behavior and emotional damage inflicted by non-disabled people. This form of disablism works along psychological and emotional pathways and 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 (Reeve, 2002, 2006). Psycho-emotional disablism can thus place further limits on who people can be by shaping an individuals' 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 or daughter who displays frustration and keeps complaining about his/her mother's loss of memory.

Policy and Place

There is currently significant interest in dementia in both the UK. Indeed, the costs of caring for an ageing population with 'high support needs' looms large in the minds of governments and policy-makers not just nationally, but internationally. We do not have the space here to critically review the significant raft of reports on services and strategy published in recent years, but it is informative 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 a significant impact on governments and policy-makers internationally, flags up the projected patterns of ageing and dementia across the world:

> *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 in place

As e have noted, adapting the social model of disability and anti-disablist thinking to people with dementia requires us to consider not just the social and institutional disadvantage that those with dementia can experience, but also the ways in which this is played out through the everyday places they inhabit.

Those with dementia can lose their 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 them 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 (Beresford *et al.*, 2011). This challenge has more recently been taken up through the Dementia Friendly Communities initiative – spearheaded by the Alzheimer's Society and the Joseph Rowntree Foundation in 2012. This initiative is designed to work collaboratively with people with 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. The overall aim is to enhance inclusion and facilitate the ability of those with dementia to achieve greater independence, choice and control over their lives.

This approach was originally developed to counter the exclusion of people stigmatised by poor mental health. This not only required us to develop a greater understanding of the relationship between the individual and the wider community, but also required us to think about how society judges the value of individuals and responds to mental ill-health. It means we need to think about how 'risk' should be defined, and what is meant and understood by the participation and empowerment of individuals within a community. Understanding and valuing difference can only be resolved through the engagement of all involved.

With regard to dementia, these practices are 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 somehow deviant or abnormal 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 particular places 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. So an accepting community becomes 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 also important. The short-term memory loss associated with dementia means that new and unfamiliar places can add to the confusion already experienced by a person with dementia. Research has already demonstrated that respite care in residential settings can be problematic in this respect.. 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 de-personalised – something that often happens in collective institutional settings.

Concluding Comments

We have aimed in this article to illustrate how applying the social model of disability to dementia can provides some important insights and observations that might help us rethink our approach to dementia. 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 how different theoretical perspectives can be drawn upon to help *explain* the social barriers highlighted by the social model of disability and how this has relevance for understanding the exclusionary physical, social and emotional barriers experienced by people with dementia. Our 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.

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