

# **Dementia, Disability Rights and Disablism: understanding the social position of people living with dementia**

**Carol Thomas and Christine Milligan**

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## **Points of Interest**

- This paper asks the question: is it helpful to think about people living with dementia as disabled people?
- The paper looks at the disability and human rights of people living with dementia.
- The paper discusses how some writers in disability studies have applied the *social model of disability* to people living with dementia.
- The paper looks in detail at some of the challenging sets of ideas that are posed by linking disability and dementia.

## **Abstract**

This paper considers the recent history and consequences of positioning people living with dementia in the realms of disability, disablism and disability rights. The geo-political focus is the United Kingdom (UK) and neighbouring resource-rich nations in the global North. The first section examines the growing trend of identifying 'dementia' with 'disability', a trend fuelled by the expansion of dementia-related activism and research. The second section focuses on how researchers who have published in *Disability & Society* have applied the social model of disability to individuals living with dementia. The third section discusses three conceptual challenges that lie ahead for those who choose to research and theorise the dementia/disability connection. These challenges concern: theorizing dementia as disability; understanding intersectionality in dementia contexts; and identifying positive 'care' and 'support' for people living with dementia.

## 1. Introduction

Dementia<sup>1</sup> is a category of illness that is of growing concern to older people, the general public, professionals and policy makers (WHO 2012, 2016a, 2016b; Alzheimer's Society 2014, 2016a, 2016b). In 2016, the World Health Organization (WHO 2016c) reported that 47.5 million people worldwide have dementia and that there are 7.7 million new cases every year. This 21<sup>st</sup> century epidemiological expansion of dementia, especially Alzheimer's disease, has spurred on public debate about responses and potential solutions. Medical specialists approach dementia as a pathology and tell us that individuals with one of the various forms of dementia move through *early*, *middle*, and *late/advanced* stages of neurological decline, and that these temporal changes are marked by a complexity of capacity loss: cognitive, psychological and physical (WHO 2012).

This paper considers the recent history and consequences of positioning people living with dementia in the realms of disability, disablism and disability rights. Before exploring these themes it is necessary to understand that living with any form of impairment and discrimination at individual, household, community and societal scales will be shaped profoundly by the geo-political specificities involved. That is, we follow the advice of other writers in disability studies by avoiding making inappropriate cross-cultural assumptions (Soldatic and Grech 2014; DaGS 2016; Grech 2012, 2015). Thus, the consequences of living with dementia will be specific to place and time, and in the global South will be moulded by particular neo-colonial economic and cultural landscapes. In this spirit, we state that the analysis in this paper stems from perspectives in the global North, and focuses especially on ideas about living with dementia in the UK.

The first section of the paper examines the growing trend of identifying dementia with disability, a trend fuelled by the expansion of dementia-related activism and research. This leads to a section focusing on how researchers who have published in this particular journal have applied the social model of disability to individuals living with dementia. The third section discusses three conceptual challenges that lie ahead for those who choose to research and theorise the dementia/disability connection.

## **2. Dementia and disability**

Whilst the connection between disability and ageing is a well-established arena for activism and research (BADIN 2017), the disability/dementia linkage has been forged incrementally. Indeed, activists and researchers within disability studies in the global North have been relatively slow to refer to people living with dementia as disabled people, but recent years have witnessed a forward leap in this regard. This has been captured by Tom Shakespeare, Hannah Zeilig, and Peter Mittler in their paper: *Rights in mind: Thinking differently about dementia and disability* (Shakespeare et al 2017):

We are also interested in whether categorizing dementia as a disability may help us to explore some of the ways that barriers and discourses shape experiences of the condition. Perhaps most importantly, we hypothesize that seeing dementia as a disability could place people with dementia, as self-advocates, at the centre of their own stories, and help provide an enabling identity. (Shakespeare et al 2017: 2).

This dementia/disability linkage is largely in response to i) dementia activism and ii) academic work on dementia in a range of social scientific disciplines, picking up on the

influential early work of Kitwood (1979) and Lynam (1989). For example, in the shadow of the UK's Disability Discrimination Act (DDA 1995, 2005) activists in the Scottish Dementia Working Group (SDWG/DEEP: 2017) have pioneered the establishment of a UK-wide network of groups committed to the empowerment of people with dementia. On the international stage, examples of activist innovations have included the establishment of the *Dementia Alliance International* in 2014 (DAI, 2017). DAI's stated mission is to eradicate stigma and discrimination, mirroring the longstanding *disability rights* agenda and echoing Charlton's (1998) disabled people's movement (DPM) slogan *Nothing about Us Without Us*. DAI's webpages foreground self-advocacy through its membership message: "... [we are] exclusively for people with a medically confirmed diagnosis of any type of a dementia from all around the world" (DAI 2017). Turning to the academic arena, examples of relevance include publications by researchers in the intellectual disability field who have studied the association between rising life expectancy and increasing prevalence of dementia amongst people with learning disability (Janicki et al 1996; Bigby 2008; Fahey-McCarthy et al 2009; see also IHAL 2017).

Once *being disabled* and *having dementia* are connected and conjoined, it seems to be logical that the social gains already achieved by disability rights activists and supportive policy makers acquire expanded relevance. That is, people diagnosed with dementia, and their supporters, become eligible – at least nominally - for protections afforded by legislation against social discrimination on the grounds of disability. In the UK, of particular importance in this regard is the *Equality Act* (2010), together with the UK endorsed *United Nations Convention on the Rights of Persons with Disabilities* (UN CRPD 2006). These rights include the right to full and appropriate access to medical services for diagnostic and

treatment interventions, and to social care services of the highest quality if/when these become necessary (MHF 2015, 2016). However, it is important to note that disability rights agendas of relevance to disabled people in general have not been fully implemented in the UK or elsewhere (Oliver and Barnes 2012; Roulestone and Prideaux 2012). Legislative advances across the globe have been accompanied by implementation blockages and partial reversals bound up with neo-liberal economic and political developments (Barnes 2012; Grech 2015; DaGS 2016). Nevertheless, formal steps have been taken to strengthen the social position of disabled people in the UK and elsewhere, steps that – at least on paper - are of protective relevance to people with dementia (MHF 2015). Of course, whether or not individuals newly diagnosed with dementia actually come to self-identify as disabled people is an entirely different matter. Indeed, many communities of people with acquired impairments do not identify immediately, or ever, as disabled people, but they nonetheless qualify for disability rights and related legal protections (EHRC 2016).

Over the last two decades, the UK has witnessed individuals' growing willingness to 'come out' with dementia, accompanied by their supporters and allies (Watkins et a. 2006). One of the best-known public campaigners with dementia was the late author, Terry Pratchett. Other high profile figures have joined public campaigns 'as and on behalf' of people living with dementia (for example, actors Dame Judi Dench, Tony Robinson and Prunella Scales). A corollary has been a growing media interest in seeking out celebrity and lay voices talking about the social and individual challenges posed by living with Alzheimer's disease and other forms of dementia. In short, the voices and perspectives of people living with dementia now have presence in the social arena.

### **3. Dementia and disability: applications of the social model of disability**

This section focuses on research on dementia within disability studies, and draws upon publications in this journal, *Disability & Society*, in particular. Overall, it is hard to deny that there has been a general tardiness among researchers to associate disability and dementia, partly explained by the complex history of disability politics over the last 50 years in the global North (Campbell and Oliver 1996; Turner and Stagg 2013; Burch and Rembis 2014). On the one hand, disability studies activists and scholars have focused on disabled adults of working age, together with disabled infants and children. This has meant that less attention has been given to older people who acquire impairments as their bodies age, or to disabled people who live into old-age (Priestley 2003; Beresford and Thomas 2015; but for an exception see Zarb and Oliver 1993). On the other hand, although disability studies activists and scholars knew of the emergence of the concept *ageism* in the social sciences in the latter quarter of the 20<sup>th</sup> century (Phillipson 2013), this did not hasten the making of what now appear to be obvious connections between forms of discrimination associated with being old and being disabled.

In addition, the delay in making links between dementia and disability has also been tied up with long-standing struggles within the disabled peoples movement to be ever more inclusive of *other* groups of disabled people, for example people who primarily identify as 'gay', 'Black', 'Deaf, or 'psychiatric system survivors' (Beresford 2002; Shakespeare 2013; Sayce 2016). Indeed, it took some years for calls for diversification to translate into any meaningful embrace of people whose conditions are labeled by medical professionals as, for example, 'intellectual retardation' or 'mental illness' (Beresford 2002; Beresford et al. 2011; Goodley et al. 2012; Shakespeare 2013; Spandler et al. 2015; Sayce 2016). A recent

manifestation of this move to embrace diversity is illustrated by disability studies' engagement with '*mad studies*' (MSN 2016). Tension also remains about how to include and support people living with 'chronic' or long-standing illness, wherein physical conditions alter significantly over time (Thomas 2007). All of these political tensions about diversification connect, in a fundamental sense, to ongoing theoretical arguments within disability studies about the nature of impairment, the body, and embodiment (Thomas 2007; Goodley et al. 2012; Shakespeare 2013).

For those researchers who were among the first to observe a link between disability and dementia, and who sought to publish their findings in *Disability & Society*, it is not surprising that they turned for inspiration to the UK's totemic and philosophically realist *social model of disability* (Blackman et al. 2003; Dorenlot 2005; Beattie et al. 2005; Davis et al. 2009; Brittain et al. 2010). Echoing the earlier writings of Paul Hunt (1966), Vic Finkelstein (2001) and the DPM (UPIAS 1976) on institutionalized 'care' provision, research on living with dementia paid particular attention to the social activities and collective practices of medical professionals and 'care' workers, especially those working with people in the later stages of dementia. In essence, applying the social model meant examining whether individuals who served as carers imposed any disablist social barriers upon those living with dementia, in everyday person-to-person interactions either in households or within institutions. From the start, it was understood that the imposition of problematic social barriers might be undertaken inadvertently or benignly - in the name of serving the best interests of increasingly dependent people. However, it was known from historic research on disabled peoples' experiences (Hunt 1966) that such practices may be undertaken purposively in the belief that 'dependents' have lost their personhood and 'must' be

contained and controlled. Containment of people with dementia certainly became of concern to policy makers as ‘patient’ numbers expanded: by 2016 there were 850,000 people with dementia in the UK, two thirds of whom are women.

Through the publication of research on living with dementia in this journal, multiple dimensions of dementia-related discrimination and social exclusion have come to light (Blackman et al. 2003; Dorenlot 2005; Beattie et al. 2005; Davis et al. 2009; Brittain et al. 2010). That is, the changes in individuals’ behavior and personhood bound up with having dementia have been associated with social responses that sometimes amount to abuse and oppression. Table 1, sourced from Thomas and Milligan (2015), provides a summary of the findings of this body of research.

**Table 1: Examples of social barriers imposed upon people living with dementia (reported in *Disability & Society* by Blackman et al. 2003; Dorenlot 2005; Beattie et al. 2005; Davis et al. 2009; Brittain et al. 2010).**

<b><i>Individual attitudinal and behavioural barriers</i></b>
<ul style="list-style-type: none"> <li>• Lack of understanding on the part of some people (e.g. formal and informal carers, family members, the general public) of the behaviours, personality changes, and alterations in physical capacity that come with stages of dementia.</li> </ul>
<ul style="list-style-type: none"> <li>• Lack of sympathy and tolerance toward people with dementia on the part of some other people.</li> </ul>
<ul style="list-style-type: none"> <li>• Failure of some people to recognise the practical and spatial difficulties faced by people living with dementia (e.g. difficulty recognising places and individuals, way-finding, locating items) – especially in the middle and late stages of dementia.</li> </ul>
<ul style="list-style-type: none"> <li>• Failure of some people to understand how easy it is for anxiety, fear and uncertainty to take hold in the minds of people living with dementia – e.g. if the latter are in unfamiliar</li> </ul>

surroundings and settings.
<ul style="list-style-type: none"> <li>• Failure of some people to find ways to communicate with people living with dementia, especially where spoken language is minimal, confused or absent.</li> </ul>
<ul style="list-style-type: none"> <li>• Failure of some people to recognise and respond to the non-verbal ways that people living with dementia may try to communicate.</li> </ul>
<ul style="list-style-type: none"> <li>• Some peoples' misrecognition and misunderstanding of behaviours and expressions displayed by people living with dementia – e.g. these may be wrongly attributed, in an ageist fashion, to 'just being old'.</li> </ul>
<ul style="list-style-type: none"> <li>• Failure of some individuals to ask people living with dementia what they want, how they feel, and what would help to improve things in their lives etc. That is, treating the latter as infantile and passive.</li> </ul>
<ul style="list-style-type: none"> <li>• Cruelty, violence and abuse directed at people living with dementia – by some others.</li> </ul>
<ul style="list-style-type: none"> <li>• Lack of respect, dignity and compassion awarded by some individuals to people with dementia – at all stages of the disease, including during end of life 'care'.</li> </ul>
<p><b><i>Barriers that become embedded in institutional and collective practices</i></b></p>
<ul style="list-style-type: none"> <li>• Failure by some people to design or adapt items, interiors, buildings, and external environments like streets and gardens. Such adaptations could support people living with dementia by assisting them to remain active, engaged and comfortable. This requires consultation with people living with dementia, as well as careful planning, flexibility and the creative use of technology.</li> </ul>
<ul style="list-style-type: none"> <li>• Systemic denial of choice, self-determination and citizenship rights to those with dementia by some 'carers' (e.g. around food preferences, expressions of sexuality, lifestyle, decision making).</li> </ul>
<ul style="list-style-type: none"> <li>• Failure of some people to assist others in obtaining an early diagnosis of dementia - because of the social stigma and fear attached to forms of dementia.</li> </ul>
<ul style="list-style-type: none"> <li>• Weaknesses and failures on the part of medical treatments for dementia, in addition to poor health and social care systems (statutory and voluntary) for people living with dementia.</li> </ul>
<ul style="list-style-type: none"> <li>• Failure by some services to support the needs of family and other informal carers of people living with dementia.</li> </ul>

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| <ul style="list-style-type: none"> <li>• The use of neuroleptic drugs in ‘care’ services, as a means of quieting and controlling people living with dementia.</li> </ul>   |
| <ul style="list-style-type: none"> <li>• The use, by some people, of stigmatising and degrading images and representations of people living with dementia in the media and wider culture (e.g. in newspapers, film, television, theatre, art, literature etc.).</li> </ul> |
| <ul style="list-style-type: none"> <li>• Inadequate or absent state legislation and official policies drafted in the interests of people living with dementia.</li> </ul>  |

Source: adapted from Thomas and Milligan (2015)

Table 1 illustrates that researchers found that many and varied forms of oppressive and exclusionary practice were in operation in dementia-related contexts. Put another way, there is evidence that disablism emerged, in numerous ways, in the lives of people living with dementia.

In more recent research, Ruth Bartlett (2014) has moved ideas along by switching attention to the perspectives and campaigning activities of people with early-stage dementia themselves. This echoes the DPM’s principle of prioritising the personal perspectives and experiences of disabled people, in the spirit of the mantra *nothing about us without us* (Charlton 1998). Bartlett explored individuals’ resistance to negative stereotyping associated with being diagnosed with dementia, and found that individuals’ campaigning efforts sought to sustain their citizenship rights. However, using diary-interview methods of data collection, Bartlett argued that peoples’ campaigning work could be a double-edged sword because, on the one hand, her respondents reported that their activism was both ‘energising and reaffirming’ but, on the other hand, was the cause of ‘...dementia-related fatigue and oppression’ (ibid: 1291). The latter was linked to coming up

against “normative expectations about what someone with dementia ‘should’ be like” (ibid: 1291). Bartlett was thus led to conclude that the struggle for citizenship rights has only just begun for people living with dementia, and their supporters.

In another paper Geraldine Boyle (2014) reported research that involved interaction with individuals with more advanced dementia. Her publication explored whether people with late-stage dementia had *agency*, something commonly denied by formal and informal carers, and in the wider culture. She concluded that people with advanced dementia adopted non-conventional ways of expressing their wants and wishes, and therefore that standard social scientific conceptions of what constituted agency were too limited in their concentration on “rationality, language and individualised agency” (2014: 1130):

The study highlighted that people with dementia who lack deliberative capacity can nonetheless demonstrate creative capacity for agency. A more expansive concept of agency is needed in social science theory that is informed by the experiences of cognitively disabled people. (Boyle 2014: 1130)

#### **4. Challenges ahead in understanding dementia, disability rights and dis/ablism**

Although the *Disability & Society* papers referred to above, and those published in other journals, indicate that research on living with dementia is now well established, much thinking remains to be done to *theorise* the individual and social consequences of dementia. Within disability studies, linking disability and dementia raises difficult theoretical

challenges, some of which are explored in this section of the paper. The point of departure chosen here is to briefly summarize two core theoretical perspectives in use in disability studies (reflecting the social sciences more generally). The first is the *realist* (or *critical realist*) perspective wherein biomedical definitions of impairment are accepted as ‘real’ (albeit always bio-socially contingent), but are then set aside on the grounds that the DPM’s primary and ‘proper’ focus is on *disablism* and the consequent political struggles against all forms of oppression predicated upon designated impairments (Thomas 2007; 2015a, 2015b; Oliver and Barnes 2012). ‘Standpoint identity politics’ logically follow from this starting point. The second perspective is poststructuralist *anti-essentialism* wherein the bio/social enterprise of constructing and dichotomizing the properties of *normal* and *abnormal* bodies/minds are questioned and deconstructed. This second perspective re-orientates attention to *ableism*, that is, to the ideas about *normativity* that are constructed and reproduced by those whose bodies and minds are deemed to constitute ‘the normal’ (Tremain 2005; Campbell 2009; Shildrick 2009; Goodley et al. 2012; Mitchell and Snyder 2015). Publications using this second perspective invariably critique identity politics, and usually opt for the *critical disability studies* nomenclature. So, how do these perspectives play out in the following challenges?

### **Challenge 1: theorizing dis/ablism and dementia**

It has long been acknowledged within disability studies that whilst the social model of disability is a powerful political tool it is not a *theory* of disability (Oliver and Barnes 2012). That is, the model is limited in its explanatory power. Whilst social barriers are identified, their coming into existence is not explained *per se* (Thomas 2007). This means that once dementia and disability are linked, the core theoretical question remains as follows: why is

it that the social relationship between individuals designated as either 'having' or 'not having' dementia often involves the social oppression/exclusion of the former group by the latter majority (individually, institutionally, structurally)? This is a difficult question to answer, as are the parallel questions in other branches of equality and diversity studies: why does sexism exist? Why racism? Why homophobia?

So, how can the two theoretical perspectives summarized above be applied to theorizing the link between dementia and disability? We offer some brief observations here, necessarily simplistically and crudely expressed, in the hope that researchers and activists will move ideas on by agreeing or disagreeing:

i) *Realist philosophical perspectives on linking disability and dementia.* Realist perspectives (with theoretical labels such as materialist, Marxist, feminist materialist, or critical realist) would highlight the way that capitalist economies have no use for people who live with dementia because such people are deemed to be cognitively impaired and 'too old'. This is because Western cultural criteria for being socially valued are closely tied up with either: i) being able to work for wages/salaries (now or in the future); or ii) being able to contribute to the economy through unpaid care work (e.g. looking after grandchildren), or through financial spending and/or investment. In short, the social value of individuals is measured by their ability to fit into economic roles that generate pecuniary profit (directly or indirectly), and/or by their financial self-sufficiency (Thomas 2007). The implications are that people with dementia are perceived to be a problematic and dependant population who should be: kept out of the way of essential social interchanges and mainstream activities by being housed in family homes or 'warehoused' in residential care institutions. Residential care

may mean placing people with advanced dementia under the control of the medical and 'care' professionals, and behaviourally restraining them through pharmaceutical regimes. Accompanying these economically driven exclusions are cultural representations of people with dementia as: burdensome; a nuisance; a drain on societal resources; a social problem that has to be managed and contained by families and designated authorities.

ii) *Anti-essentialist perspectives on linking disability and dementia.* These perspectives (with theoretical labels such as poststructuralist, postmodernist, feminist postmodernist, anti-foundationalism, post-conventionalist) would tend to approach the disability and dementia connection by highlighting the cultural meanings constructed by those designated 'the normal' - in their centres of institutional bio-power. Foucault's ideas have been particularly influential in forging this theoretical approach (see Corker and Shakespeare 2002; Tremain 2005). In today's globalized world, the normative bodies and behaviours that carry most social value are those associated with 'youth and beauty', and those suffused with intellectual vitality (Campbell 2009; Shildrick 2009; Goodley et al. 2012). The societal implications are that people who live with dementia are deemed 'abnormal', 'undesirable', and 'weird' – even 'disgusting'. These negative cultural meanings would be genealogically traced back to specialist and influential discourses that have assumed historical authority in society, originating within organisations such as: the Church, judiciary, state officialdom, scientific authorities, and medical schools (Campbell 2009; Goodley et al 2012). In matters of impairment and disease, it is members of the medical and pharmaceutical professions who hold privileged discursive power. That is, scientific knowledge about dementia permits its specialists to define and treat designated abnormalities of the body and mind, and to oversee regimens of treatment and containment. In turn, medical ideas shape thinking in

other cultural institutions such as the media, and informs knowledge across the wider society. In this way, everyone starts to share in and elaborate ideas about what it means to be 'demented' and possibly dangerous. For anti-essentialists, it follows that the performance of oppressive ableist practices towards people living with dementia is inevitable. Authoritative ideas seem to justify: shutting people up in institutions; controlling challenging behaviours through pharmaceutical solutions; and ignoring what people with dementia say they want. This stance suggests that campaigning for human rights and beneficial changes for the oppressed needs to begin in the cultural realm, that is, in the realm of ideas and knowledge. However, we note that very little about dementia has yet been published in this theoretical vein.

The challenge is to take these two sets of theoretical ideas forward, so that sophisticated understandings of how to link disability and dementia are further developed. Some readers may think that other theoretical perspectives hold more promise. Moreover, there is no doubt that much can be gained by referring to relevant research and theorising in other disciplinary arenas, such as sociology, social geography and social gerontology (see, for example, Gilleard and Higgs 2000; 2013; Milligan 2003, 2009; Mitchell 2004; Mitchell et al. 2005; Roberts et al. 2012; Phillipson 2013; Bailey et al 2013; Keady et al. 2013; Twigg and Martin 2015).

### **Challenge 2: building-in diversity and intersectionality**

So far in this paper, people living with dementia have only been distinguished from each other by their disease stage (i.e. early, middle, advanced). This is far from satisfactory and a key theoretical challenge is to build on and integrate analyses of social diversity (see, for

example, Daker-White et al. 2002; Beattie et al. 2004, 2005). Like any other social actor, individuals living with dementia carry a rich combination of other culturally meaningful social markers that distinguish one person from another, such as: male or female, black or white, straight or gay (LGBT), relatively old or middle-aged. And people embark on their lives with dementia in very contrasting socio-economic circumstances, usually following decades of differential access to resources and opportunities. In this way, matters of social diversity, together with multiple dimensions of inequality, mix in intricate ways when dementia inhabits individuals' biographies (Thomas and Milligan 2015). A variety of social markers, sometimes fluid and shifting, accompany ascribed identities and self-identities through the life-course. The concept of *intersectionality* can play a useful role here. This widely used feminist concept was developed precisely to understand the consequences of the overlapping and integrated fragments of our identities: our gender, ethnicity, sexuality, age and social class (see McCall 2005; Walby et al. 2007; Bilge 2010). A considerable quantity of empirical research is required to unpack these diversity themes when pursuing the disability and dementia link.

The fragmented nature of personal identities reminds us not to homogenise people into categories such as 'the disabled' or 'the old', and signals that the self-advocacy initiatives set up by people living with dementia invariably encompass diverse lives. Nonetheless, balancing 'sameness' and 'difference' is always difficult, and it is not surprising that campaigning organisations such as *Dementia Alliance International* and *BADIN* foreground themes of commonality and community to maximise their public impact.

Ageism is an obvious concept that needs to be brought into studies that link disability and dementia. This is a dimension of social oppression that social scientists have explored for many decades, noting that reaching older adulthood can operate, independently, to undermine individuals' social status and living standards (Walker 1980; Phillipson 2013; Higgs and Rees-Jones 2009). Important work on supporting the 'user involvement' of older people in general has also been published (see, for example, Carter and Beresford 2000). Being diagnosed with dementia brings the socially constructed phenomena of *ageism* and *disablism* together in original ways. In UK contexts some encouragement for exploring this interface is found in the webpages of the *Equality and Human Rights Commission* (EHRC 2016). The EHRC has considered the fundamental similarities between social inequalities experienced by a range of social groups, and has made connections between the social processes and mechanisms involved. This has eventually resulted in unifying legislation: the *Equality Act* (2010) and the Act's follow-up *Equality Duty*.

The challenge to take full account of dimensions of social diversity when theorising the link between disability and dementia is certainly daunting, but hopefully new research will make progress.

### **Challenge 3: Understanding 'abuse' in dementia contexts**

Attention was drawn in Table 1 to examples of abuse that people with dementia experienced when being 'cared for' by family members or paid care-workers, or when simply interacting with other individuals. Abuse can vary in intensity and take many forms: physical, psychological, emotional, financial or sexual (Boye and Yan 2016).

Linking disability and dementia necessitates entering the difficult territory of identifying and understanding abuse in supposedly supportive inter-personal scenarios. The challenge is to explain the cause and manifestations of harmful behaviors that are at work at the micro social scale, so that preventative measures can be promoted. Of course, writers in disability studies who focus on other communities of disabled people are no strangers to research on abuse in intimate, familial and formal organisational contexts (Morris 2001; Roulstone and Mason-Bish 2012; Sobsey 1994).

The abuse of people living with dementia in both domestic and residential settings has been addressed by academics in other disciplines (Dong et al. 2014; Boye and Yan 2016; McCausland et al. 2016), but all conclude that research in this field is under-developed and incomplete. For example, Boye and Yan's (2016) systematic review of published literature on 'abuse of older persons with dementia' highlighted the definitional and methodological inconsistencies involved in the field, and noted that reported prevalence rates of abuse varied significantly (ranging from 0.3% to 78.4% in community contexts, and 8.3% to 78.3% in institutional settings (2016:1)). Another indication that research of this type is under-developed is that the topic of social diversity amongst the abused is largely unexplored. In part, this is because researchers immediately encounter methodological challenges when trying to isolate overlapping dimensions of identities: gender, age, 'race', sexuality etc. For example, is abuse among older women with dementia a consequence of long-standing domestic abuse or of dementia-related 'elder' abuse? (McClausland et al. 2016: 482):

There is evidence to suggest that domestic abuse occurs more often in partners or families where someone is suffering from dementia. However, the research is

very limited in this area, does not focus clearly on domestic abuse rather than elder abuse, and does not look in any detail at the trajectory of abuse in relationships after the onset of dementia. More research is needed in this area, particularly to define the sub-set of intimate partner abuse within the larger cohort of elder abuse, and investigate the link here with dementia.

A social-relational concept in disability studies that may be of analytical assistance in understanding abuse (or its opposite) in the disability/dementia link is *psycho-emotional disablism* (Thomas 1999). This concept, now widely used in disability studies' research, encourages a close look at behaviours in inter-personal relationships:

In inter-personal settings, this refers to the culturally contextual use of words, actions and images by those deemed 'normal' that have the effect of undermining the emotional well-being of people categorised as 'impaired'. Such disablism may be enacted purposively in order to harm (e.g. 'hate crime'), or may be enacted 'in good faith' (e.g. by well-meaning parents). The impact of psycho-emotional disablism on personhood is often profound - because the damage inflicted works along psychological and emotional pathways to injure disabled individuals' self-esteem, personal confidence and ontological security (adapted from Thomas 2015: 6).

It would certainly be of value to see if new knowledge about dementia-related abuse (subtle or explicit) can be generated by the use of this concept in research, especially research that is sensitive to the need to take account of dimensions of social diversity.

Thankfully, in Western societies in the twenty-first century, social relationships between people designated as having or not having dementia are certainly not normally ones that involve the systematic brutalization of the former by the latter. Instances of outright violence or hate crime are the exception, not the rule (Watson et al. 2012). Indeed, family members, friends, or professionals and paid carers are likely to respond to the needs of people with dementia with a positive desire to assist and ease anxiety. And many institutions in the field have flourished by being high-quality places of specialist dementia-care, where care practices have been specially formulated to meet the needs of those diagnosed with Alzheimer's disease or related conditions (WHO 2012). This means, of course, that there is also a requirement for research on the experiences and needs of carers/supporters, not least about the often very distressing experiences of spouses who struggle to cope as their partners begin to move through the stages of dementia (see for example, Hennings 2016). Moreover, some carers may become the *victims* of abuse if the manifestations of dementia are violent and aggressive behaviors (Boyed and Yan 2016).

Turning briefly to safety and inclusion at the neighbourhood scale, there is no doubt that individuals living with dementia can benefit if they dwell in supportive local communities. Such *Dementia Friendly Communities* (Mitchell 2012) have been championed in the UK by organisations such as the Joseph Rowntree Foundation and the Alzheimer's Society. Emphasis has been placed on achieving physically accessible, accepting and enabling communities, where most residents have an understanding of dementia and offer help. Such communities can enable people with dementia to exercise greater degrees of choice and self-control in daily life, so that they can negotiate environments safely and with confidence. However, such innovative developments have attracted recent criticism from a

disability rights perspective:

Even a phrase like 'dementia friendly', while apparently positive, could be considered patronizing and inappropriate. The implication is that the solution to the dementia problem is for people without dementia to be kind and welcoming of people with dementia. But if the problem includes socially imposed barriers, devaluing and even human rights violations, then the term 'friendly' might be judged an inappropriate response which we would not use for other excluded groups. (Shakespeare et. al.: 7).

This criticism demonstrates that forging the dementia/disability link generates new arenas for debate and controversy. In this context, much can be learnt from the volume of research by disability studies specialists on the inclusion and support needs of other communities of disabled people, for example people with learning disability (for example, Williams and Heslop 2005).

## **5. Summary**

This paper has explored some of the consequences of thinking about people living with dementia as disabled people, focusing on the United Kingdom and resource-rich nations in the global North. Three themes have structured the paper: the conceptual joining of 'dementia' and 'disability' in recent years; the application of the social model of disability to people living with dementia by researchers who have published in this journal; and the exploration of three conceptual challenges that lie ahead when theorizing and researching the dementia and disability connection. It has been emphasized throughout that the recognition of the disabled status of people living with dementia gives rise to eligibility for

anti-discriminatory disability rights together with related human rights and legal protections – for both people with dementia and their supporters. Legislation of special relevance in the UK is the *Equality Act* (2010), and the international *United Nations Convention on the Rights of Persons with Disabilities* (UN CRPD 2006). To our knowledge, this anti-discriminatory legislation has not yet been tested in dementia-related cases, but the potential is there to do so. In resolving the theoretical and research challenges that lie ahead, we believe that much can be gained by promoting dialogue between the social and health science disciplines that are participating in current dementia-related scholarship. And the next few years will be important for establishing the success and direction of travel of social movements committed to securing the human rights of people living with dementia.

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## NOTES

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<sup>1</sup> In brief terms, dementia is an umbrella term commonly used in biomedicine and wider society to describe a range of chronic conditions that cause damage to the brain. Alzheimer's disease is the most common condition, but others of particular note are vascular dementia, Lewy body dementia, and Fronto-temporal dementia (WHO 2012). Associated losses in comprehension typically encompass attributes that are heavily socially stigmatized, such as: loss of memory; language skill confusion and deterioration; diminishing capacity to carry out everyday tasks; experiencing hallucinations. The manifestation of these cognitive impairments is always individualized and variable, and elides predictive certainty – but overall, individuals move progressively through, *early*, *middle*, and *late/advanced* stages of dementia, and experience a mix of changes in their cognitive, psychological and physical capacities (WHO 2012).