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Article:

Changing the narrative: The role of frontline worker attitudes and beliefs in shaping dementia friendly services in England

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Applying the main principles of the Social Model of Disability as a guide, this paper argues that the attitudes and beliefs of staff and volunteers employed in frontline service delivery can play an important role in the achievement of dementia friendly communities, particularly through influencing the types of services offered. This position is supported through findings of an evaluation of an awareness raising intervention run by Age UK, aimed at organisations which provide services for people living with dementia in England. The paper contributes to an understanding of the cultural climate within frontline service delivery, which is often neglected in favour of discussions around meeting more immediate care and support needs. More specifically, it reflects on whether there is a need for an additional conceptualisation within the discourse around dementia friendly communities which ensures inclusion of the cultural environment.

Keywords: Dementia Friendly; Social Model of Disability; culture, attitudes and beliefs

Points of interest

- This article finds that the views held by staff and volunteers who deliver services can influence the types of services available to people living with dementia, and the extent to which this group can shape those services.

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- This article shows how raising awareness of dementia through offering training and support can lead to more services being offered to people living with dementia.

- This article encourages a new discussion about how phrases which refer to ensuring people living with dementia are more included in their local community, such as dementia friendly or dementia positive, are useful.

Introduction

Dementia refers to a range of conditions that cause damage to the brain, which in turn can impact on a person's memory, thinking, language and ability to carry out everyday tasks (Mental Health Foundation 2015, 5). Ensuring communities become more tailored to the needs of people living with dementia is vitally important, with the Alzheimer's Society (2018) pointing out that many people living with the condition can feel cut off from society, with over a third reporting feelings of loneliness. As well as this having a negative impact on quality of life, it also prevents the person living with dementia from making a valuable contribution to their local community.

In recent years there has been an increased interest around how communities can ensure people living with dementia are enabled to participate in their local neighbourhood. This has led to the development of dementia friendly communities (or some variation) being adopted in a number of countries (Japan, USA, Australia, and parts of Europe). Crampton et al. (2012, 4) refer to dementia friendliness as supporting the development of an asset as opposed to a deficit driven approach, which the Alzheimer's Society describe as:

Where people with dementia are understood, respected and supported, and

confident they can contribute to community life. In a dementia friendly community

people will be aware of and understand dementia, and people with dementia will

feel included and involved, and have choice and control over their day-to-day lives

(Crampton et al. 2012, 4)

At the time of writing over 80 areas in England are classified as dementia

friendly (for more information, see Alzheimer's Society 2018). The importance of

giving regard to the social experience of people with dementia is highlighted in a

document produced by the World Health Organization (WHO) and Alzheimer's

Disease International (2012), which identified dementia as a public health priority,

and can also be found in earlier guidance documents (such as Living Well with

Dementia: A National Dementia Strategy, Department of Health (Gov.UK 2009)).

However, the recent proliferation of dementia friendly communities in England

has been driven in large part by the Prime Minister's Dementia Challenge 2020

(Department of Health 2015; Dementia 2020 hereafter), which has set ambitious

targets in which all businesses are being encouraged to ensure services offered are

dementia friendly (LGA and Innovations in Dementia 2014, 11).

Sometimes other terms are used to denote the concept of dementia friendly,

such as memory friendly in Finland or dementia supportive communities in

Scotland (Lin and Lewis 2015). Alongside this, different countries may place

specific emphasis on particular aspects, such as dementia capable in the USA,

which focuses on upskilling staff who work in the care and support of people with

dementia, with more of a focus on needs, as opposed to ability (Lin and Lewis

2015). Some commentators have suggested that the term dementia friendly is

unhelpful, for example, Shakespeare (2017) argues that whilst the implication and

intentions are good, it can sound patronising, suggesting that people need to be kind and considerate to those with the condition (this is considered in more detail later).

Whilst the emergence of dementia friendly communities and corresponding developments relating to the accessibility of local spaces has been subject to an emerging body of research, less attention has been paid to how the attitudes and beliefs of frontline workers (in both staff and managerial roles) and volunteers may impact on what is actually offered or viewed as appropriate, as well as the role these play in the sustainability of dementia friendly communities. Lin and Lewis (2015) argue that changing beliefs alongside changes in behaviour are necessary to ensure well-being for people living with dementia. This paper has a particular interest in exploring how changing the narrative (Perkins et al. 2016, 30) around dementia can lead to beneficial culture change among frontline service delivery staff. It begins by summarising research on how dementia is conceptualised, providing an overview of the rights-based approach adopted through the Social Model of Disability (SMoD hereafter). It then goes on to look more closely at communities which are offering dementia friendly services, before discussing the Age UK run Dementia Friendly (DF) programme (Age UK is a UK charity which offers a range of support to people over the age of 50). This is followed by a discussion and some tentative conclusions.

Ageing well with dementia

Whilst accessibility is undoubtedly important, it is also necessary to explore the role that social relations (Blackman et al. 2003, 361) within communities and frontline services play. When focusing on social relations it is useful to explore the Social Model of Disability (SMoD), which draws us away from a more medicalised

approach through adopting a rights-based lens (Blackman et al. 2003; Mental Health Foundation 2015). The model emerged through the disability rights movement in the 1970s and the term itself was coined by Mike Oliver (1983), who conceived the idea following publication of a UPIAS document, first published in the mid-1970s, which argued that people tend to be disabled through societal barriers, rather than due to the impairment itself (Oliver 2013). The model focuses on how individuals might experience challenges due to the way in which communities are structured, both in terms of the physical environment and culture:

> People are often disabled by the environment and the attitudes of others, as much as they are by their individual impairment (Mental Health Foundation 2015, 4)

Whilst there is some (albeit limited) literature which discusses the rights of people with dementia, viewing dementia through a social rights lens is relatively new (Mental Health Foundation 2015), as, in fact, is conceptualising a person with dementia as being disabled (Thomas and Milligan 2017). It is necessary to bear in mind that people living with dementia are not homogenous, and that we must give regard to intersectionality. That is, experiences will depend on socio-economic characteristics, gender, and so on (Thomas and Milligan 2015). Further, whilst viewed as helpful to draw on the SMoD, dementia (as with other disabilities) may have an impact on a person's ability to participate, in many cases over and above any potential barriers placed by social responses to it (Beattie et al. 2005).

There are also identified weaknesses of the model, such as those outlined by Shakespeare (2006), who argues that it fails to capture the complexity of factors that impact on the lives of disabled people. Perhaps a more fundamental issue is acknowledging the potential conflict between preventing harm and respecting the

person's right to autonomy, which can at times impede more person-centred approaches to care. For example, walking outdoors can be beneficial for health and well-being, but some people are at increased risk of getting lost and of harm (Bantry-White 2018). The authors of a systematic review which focused specifically on the management of wandering concluded that there is a need to ensure practical tools are developed to mitigate the issues inherent in balancing rights with risk (Robinson et al. 2007). Alongside this are potential ethical issues of utilising technologies to help mitigate some of these concerns (Bantry-White 2018).

While necessary to bear the above points in mind, the SMoD is nevertheless viewed as helpful. This is particularly so when we consider the evidence suggesting that the current public policy narrative around dementia tends to be stigmatising and may impact on what services are offered (returned to below). In addition, Oliver (1983) did not suggest the SMoD was an all-encompassing framework, but rather, should be used as a tool (alongside other mechanisms) to improve people's lives. Working toward ensuring the social rights of groups in society is also pertinent to wider frameworks, such as Social Quality, which identifies social and cultural cohesion, inclusion and empowerment as key to enabling citizens to not only participate fully in their communities, but to do so in a way that enhances their wellbeing (Beck et al. 1997).

Three themes, drawn from the work around the SMoD produced by the Mental Health Foundation (2015, 8), are now considered, which include:

- Identifying how the attitudes of others can be changed to improve services (attitudes and beliefs);

- Focusing on what a person with dementia can do and appreciating that people with dementia can be active citizens (inclusivity)

- Recognising that the person with dementia should be at the centre of any process and supported, where possible, to participate as fully as possible, with services doing things with people, rather than to people (a person-centred approach).

Attitudes and beliefs

Thomas and Milligan (2015, 3) argue that dementia tends to be viewed in strictly biomedical terms, with less consideration given to the way in which experiences can be shaped by societal culture, such as stigma. The Mental Health Foundation (2015) agree that the medical model tends to take precedence over a more social model viewpoint, and whilst acknowledging the importance of the former, recognise a need for a more balanced outlook. This viewpoint suggests that learned values and understandings held by individuals can permeate through the services they provide (Thomas and Milligan 2015). In other words, exploring the attitudes and beliefs of those delivering frontline services (at both the strategic/managerial and face to face customer level) can tell us a lot about what services are offered to people living with dementia (such as how perceptions of suitable services will impact on what is offered).

Dementia has historically been socially constructed as a condition which invokes negativity, stigma and fear (Mental Health Foundation 2015, 20). The importance of the social is, at least in principle, encapsulated in the policy and practice shift in recent years (Mental Health Foundation 2015), in which the focus is on ensuring people with dementia can participate fully in their communities. Yet

despite changes in discourse which has increasingly adopted a rights-based approach, stigmatising language continues to exist (Crampton et al. 2012). Correspondingly, the use of negative language is fairly widespread, which in turn feeds into negative stereotypes (Perkins et al. 2016). Indeed, the Dementia Engagement and Empowerment Project (DEEP) which brings together people living with dementia from across the UK to try to change services and policies that affect the lives of people with the condition, identified a range of terms that continue to be in use (such as dementia sufferer and burden). These are viewed as negatively influencing beliefs around what a person with dementia can do, and also impact on the perception that person may have about themselves (DEEP 2018). Whilst some positive changes are taking place, such as those documented in current dementia friendly areas (see below), it is suggested that individual beliefs will take more time to shift (Thomas and Milligan 2015).

Though a fuller discussion goes beyond the scope of this paper, it is important to note that labelling dementia as a disability in itself opens up people living with the condition to another form of stigmatisation, linked to the language associated with having a disability (Mental Health Foundation 2015). Alongside this, many people with dementia will not necessarily identify as having a disability, particularly those at an earlier stage of the condition (Thomas and Milligan 2017). Discourse around dementia and disability has further been shown to have an age dimension, with its identification as a disability being assigned more readily to younger people (Thomas and Milligan 2017). Yet conceptualising dementia as a disability (as stated in the Equality Act 2010) can assist in highlighting that people living with dementia have human rights which should be respected. This is particularly important when considered alongside recent findings which show that,

at present, dementia tends to provoke language akin to passivity (Shakespeare 2017a). So whilst the language of disability, as with dementia itself, can be stigmatising, it can also be used as a vehicle to bring people together to argue for equal rights and inclusion, ensuring society confronts the way people with dementia are disabled through negative language (Shakespeare 2017b), or what Swaffer (2015) refers to as prescribed disengagement. Prescribed disengagement refers to the fact that unlike many groups with a recognised disability, people diagnosed with dementia are advised to give everything up (for example their job and driving licence), even at early stages of diagnosis. In turn, friends and family may shun those diagnosed with the condition, such is the stigma attached to dementia.

Inclusivity

Though there is a shortage of studies which ask what services are preferred (Menne et al. 2012), research indicates that people living with dementia want to carry on living as normally as possible, for as long as possible (Crampton et al. 2012, 29). It is thus argued that this group should ideally be enabled, where practicable, to remain socially active, if they so wish. Alongside this, participating in leisure can be an important avenue through which people with dementia can retain and express their identity (Genoe and Dupuis 2011), showing that quality of life is more than merely managing the condition.

Alongside assessed impact on well-being and/or quality of life, ensuring people living with dementia can continue to access services in their local community can offer cost savings to health and social care services through increasing independence and delaying the need for intervention (LGA and Innovations in Dementia 2014). It is further pertinent in light of policy guidance

and law which stresses the importance of older people remaining physically active (such as the CMO guidelines (Department of Health (2011)) and ensuring wellbeing is placed at the centre of social care and support (for example the Care Act (2014)). We argue that ensuring people with dementia can continue to take part in activities they enjoy is inextricably linked to the cultural make up of service delivery organisations.

Inclusivity through Dementia friendly communities

The concept of a dementia friendly community arguably places more emphasis on rights based, as opposed to the medicalised dimensions of dementia, and is thus more suited to the SMoD (Mental Health Foundation 2015, 4). Crampton et al. (2012), referring specifically to developments in a city in England, found that for the most part people living with dementia felt safer navigating public spaces, found facilities and services more accessible, and felt enabled to maintain social networks and continue feeling involved in their local community. This provides an example of where real regard is being given to inclusiveness, at least in some areas (LGA and Innovations in Dementia 2014). Yet whilst some promising strides have been made, dementia friendly communities, and the rights-based language that accompanies it, is felt to have further to go, with the Mental Health Foundation (2015) stating that this would require:

> Large scale societal and cultural changes at both micro and macro levels that must be sustained, valued and nurtured (Mental Health Foundation 2015, 28)

Therefore, achievement of a rights-based environment (at the service delivery and wider community level), is perhaps more than many of the communities

described as dementia friendly are currently accomplishing. We argue that for a community to truly achieve dementia friendliness, it should go beyond questions of access and practicality, and consider if what is offered is suitable and wanted by people living with dementia. Thus, as well as assessing if surface changes at a broader level, such as to the physical environment, are evident, it is important to also consider culture changes at a micro level, relating to attitudes, and beliefs. Some initiatives, such as the Alzheimer's Society's Dementia Friends programme, an initiative aimed at changing people's perceptions of dementia (see https://www.dementiafriends.org.uk for more information) certainly looks to be going in the right direction, with over one million people becoming dementia friends. This is taking place alongside the proliferation of communities and organisations assessed as dementia friendly.

Yet whilst some organisations may be keen to ensure they offer dementia friendly services, engagement continues to be challenging for others. For example, Hare and Dean's (2015) study of dementia communities in two English cities found that some people felt that frontline staff did not always have the same level of knowledge of the condition as the organisation managers. Therefore, whilst it is necessary to have managerial support, without frontline staff being encouraged to follow strategic direction, it is not sufficient. Hare and Dean (2015) conclude that organisations must provide awareness training and support, as without this, attitudes (and arguably more crucially, beliefs) can remain reticent to change. Though the author's concur with this sentiment, it is important to consider the type and duration of training, and also, be attuned to the fact that some staff and volunteers will make this cultural transition more smoothly than others.

A person-centred approach

Though the concept of providing person-centred services is gaining traction in many countries, the concept is in fact nothing new, and can be traced to the work of Carl Rogers around person-centred psychotherapy in the late 1950s (Manthorpe and Samsi 2016). Ultimately, we argue that to be truly dementia friendly requires that people living with dementia are empowered and feel they can participate in and influence the process. The last few years have provided laudable examples of the effective involvement of people living with dementia in research and decision-making processes, such as the DEEP (2018), who have developed a range of guides aimed at organisations and communities, such as how to involve people living with dementia in recruitment, and how to ensure appropriate language is used. Similar initiatives are also beginning to emerge internationally (Perkins et al. 2016).

Person-centredness is both wider and interlinked to the themes discussed above. For example, to ensure services are inclusive people living with dementia need to be central to the development process. It also follows that for attitudes and beliefs to change to reflect the needs and capabilities of people with dementia, co-produced organisations such as DEEP (2015) have much to offer, such as advising on suitable language.

However, as with the availability of inclusive services, person-centred service provision is less developed, and where it is explored, tends to focus more on person-centred care, which has been supported in England by social care policies such as personalisation (Manthorpe and Samsi 2016), rather than broader service provision. Kirkley et al. (2011), who looked at respite care and short break services, found that organisations had not successfully incorporated person-centred services. Although resource constraints were recognised as impeding development, the

knowledge, attitudes and personal values of staff were assessed as a more significant barrier (2011, 438).

Research process

The Dementia Friendly programme

The Dementia Friendly (DF) programme provided resources and support to local Age UK partners across England to help them develop more dementia friendly services. The programme support included time with two expert consultants: the first providing training and research resources to connect people living with dementia with nature; the second to develop and test projects that can enhance the lives of people with dementia. Consultants worked with organisations to support them to shape their services to become more dementia friendly. The DF programme was delivered across three-time periods (referred to as cohorts). Cohort one included 15 local Age UK partners, with support taking place November 2013 to June 2014. Cohorts two and three included 31 local Age UK partners receiving support between July 2014 and March 2015. The programme included three days of consultancy support and a grant of £5,000, to help develop existing, or support new initiatives. In addition, all participating Age UK partners were invited to attend a range of workshops and meetings, so information could be shared.

The participating local Age UK partners received differing support, based on which cohort they belonged to. For example, cohort one was provided with support from one of the consultants only, which included an environmental audit of their premises. Later cohorts followed a different model, whereby each participating Age UK partner spent a day with both consultants. The later cohorts could then choose which consultant to spend a third support day with (if

participants preferred they could seek support from both consultants but would need to fund the extra support day themselves, which some chose to do).

Methods

The DF programme was evaluated through a qualitative, exploratory approach, which involved telephone interviews with 22 representatives of participating Age UK partners (just under half of the 46 which participated). Interviewees were chosen by Age UK to represent the full breath of organisations who took part (e.g. ensuring a mix based on size and location). Those interviewed included a mix of staff involved at the managerial and frontline delivery level. Each interview lasted approximately 45-60 minutes and followed a semi-structured interview schedule (all quotes are reported verbatim). This discussion is also based on information provided through Action Plans, which participating organisations developed independently of the evaluation. The fieldwork was ethically approved by the University of Leeds in November 2013, from the ethics committee based at the Faculty of Education, Social Sciences and Law, University of Leeds.

The interviews with frontline staff included the following:

- Representatives of eight local Age UKs from cohort one of the programme in Autumn 2014 and Spring 2015. This included a baseline interview at the beginning of the intervention, and a follow up interview carried out at the end.

- Fourteen local partners from cohorts two and three in Spring 2015 (interviews were conducted either at the end, or near the end of the intervention period).

Views were sought on motives for getting involved, the nature of the support received, main learning, any difficulties or barriers, and changes, or planned changes, to current service provision as a result of involvement. The interviews were transcribed and a thematic analysis was carried out manually, looking for common themes and recurring issues. The researcher who conducted the interview initially analysed the data, and then discussed with the research team.

Other methods which informed the evaluation but are not discussed here, included an analysis of feedback forms and a survey conducted by Age UK national of all cohort members, interviews with the two consultants, and the Project Manager. Two site visits were also carried out to observe how local Age UK partners worked with the consultants. This fieldwork has been excluded here because it did not focus on the themes explored in this paper. For a detailed discussion of the research process, please see (Author, removed for blind peer review).

As local Age UKs received funding through Age UK to work on making their respective organisation more dementia friendly, it is possible that some may have felt reluctant to offer negative feedback to the researchers'. However, we feel this was to a large extent mitigated through having access to the Action Plans of participating organisations, with some local Age UKs going on to work with the consultants, using their own money. Some critical comments were also made, and these are highlighted in the findings and discussion.

Results

Whilst participating local Age UK partners came to the DF programme with varying views around what constituted suitable services that could be offered to people living with dementia, many of those interviewed hoped to either ensure current services were more inclusive and/or were looking to develop new services. The following subsections focus on the extent to which the programme changed existing attitudes and beliefs amongst Local Age UK service delivery staff and volunteers, and whether this led to a change in actual, or planned provision. Though the findings are split into subsections, each are related. For example, challenging assumptions around what a person living with dementia can do is inextricably linked to an exploration of how the use of language was reframed; this in turn reportedly influenced planned provision of more inclusive services.

Challenging attitudes and beliefs through reframing language

It was interesting that for some of those interviewed, a fairly short support session had the ability to reframe common misconceptions around what services can be offered to people living with dementia:

> The [consultant support] was inspirational, the stuff they do is amazing, seeing what is possible, it helped me see the potential on changing perceptions, moving away from negative stereotypes (Staff member)

Alongside the support, the consultants signposted staff to other training opportunities, such as the Dementia Friends Awareness Training, run by the Alzheimer's Society. This was viewed as significantly contributing towards a shift

in perspective, helping ensure staff and volunteers were on board. At the time of the first interviews most local Age UK partners had arranged or were arranging dementia-friendly awareness training for all staff and volunteers, with some becoming dementia champions, who could then deliver future training themselves in-house.

When discussing the SMoD, the importance of tackling learned perceptions held by individuals was highlighted. Reminiscent of this, some interviewees mentioned that the information provided by consultants required staff to unlearn previous knowledge. A good example of this is that some participating Age UK partners changed the training courses that they offered to concentrate on general awareness raising, rather than on specialist information about dementia more suitable for healthcare settings:

> We changed the content and title of the dementia training course that we deliver. It was called Dealing with Dementia, it is now called Dementia Awareness, which all staff are now encouraged to attend (Manager)

Lin and Lewis (2015) maintain that use of positive communication (e.g., sounds, words, body language, images) is imperative, as this will in turn influence attitudes and beliefs. Equally the SMoD identifies that the use of stigmatising labels can undermine attempts to see past the condition. The term labelling came up a few times during the interview discussions, with some assessing the language adopted by staff as important, and certainly, linked to understandings or misconceptions that might limit what people with dementia are offered. It was found that moving away from negative representations, seemed to have the most measurable effect on service provision:

It helped [me] to look at dementia in a new light, being creative in thinking about

services. Don't pigeonhole or label in a negative way (Manager)

For this reason, the awareness raising element of the programme was particularly valued. However, reminiscent of the discussion on balancing rights with risks, the use of labels, or ensuring the person with dementia is not defined by their condition, raised concerns for some, who felt an ethical tension between including people with dementia in general services without labelling them on the one hand, and ensuring that those with potential additional support needs were identified on the other hand. This may be one of the reasons why many reported that services were geared toward people in earlier stages of dementia. Other concerns, such as ensuring the needs of other service users were met, was also discussed.

Inclusivity in service provision

Related to changing assumptions and understandings of what a person with dementia can do, there was evidence that some interviewees were starting to factor in the needs of people living with dementia when developing new services:

Now that we've got into the right mindset [being dementia friendly] is more of a

forethought and not an afterthought (Staff member)

Nearly all interviewees reported that they had either developed more inclusive services for people with dementia as a result of the DF support, or were in

the process of doing so. Some examples of ensuring the needs of this group were factored into service provision included:

- Introducing music and colour to exercise sessions
- Taking the needs of people with dementia into account when starting new physical activity groups, such as tai-chi, chair-based exercise groups, walking football, walking cricket, dance classes, walks and sports days daytrips
- Using new tools such as reminiscence boxes and memory balls
- Organising events and days out, such as a sports day and trips to the seaside:

We took some residents to the seaside to have fish and chips. One lady started crying, as she hadn't done anything like this for so long and had been stuck within four walls. So, the training, it inspired us to do something a bit different (Staff member)

There were also examples provided of local Age UK partners who started to invite people living with dementia to benefit from existing (mainstream) services, where they had previously been excluded, such as a balance and stability classes and COPD (Chronic Obstructive Pulmonary Disease) exercise groups (also, see above). To facilitate inclusion various systems were put in place, such as offering reminders (activity time and dates) and including activities which provide a change of pace in group sessions, if the facilitator notices, for example, that participants with dementia are becoming restless.

Most participating Age UK partners had a support day which focused on the importance of people living with dementia getting outdoors and keeping active, attempting to dispel the myth that this group necessarily need specialist support to do so. Not all local Age UKs initially believed that the support would be appropriate; however, some changed their minds after the support took place. For example, a few mentioned that staff and volunteers had moved away from the mindset that people with dementia were not suited to general services (also, see above), making them more aware of what they could offer:

> We weren't looking to expand activities, but [the consultant support] changed the mind of the organisation. We used to keep people in secure rooms, delivering services in buildings, apart from the garden, we hadn't recognised the opportunity to get people safely into [outdoor] spaces (Manager)

Some interviewees reported that the support day/s had enabled them to focus on what people with dementia can do and take a more adventurous approach rather than just focus on how to provide sufficient care:

> [it] helped raise awareness…Our volunteers and staff are more comfortable helping people with dementia and not trying to place them in day care (Staff member)

A few interviewees reported being encouraged by the advice on taking a positive risk-taking approach and felt it had contributed to a change in the way they approached service delivery. In fact, one of the chief misconceptions identified by interviewees at the outset was the idea that people who presented to a service with dementia would mistakenly be referred to a specialist service by frontline staff. It

was felt by some that the support provided by the programme helped move staff and volunteers away from this way of thinking:

> We used to have a risk averse attitude to delivering services, but we are now looking at making sure we are not closing down opportunities for people with dementia (Staff member)

> It's promoting the idea of being more inclusive, I feel before there was more of an emphasis placed on highlighting if people had dementia, that mainstream services weren't right for them, now a lot of people come who have cognitive difficulty and it has made [staff and volunteers] more aware of what they can offer (Manager)

One of the main benefits of moving away from a risk averse attitude was an increase in confidence amongst the staff and volunteers, as highlighted in the quote above where it was felt staff and volunteers felt more empowered. Related to this some felt it had stopped them shying away from offering a broader range of activities to people with dementia:

> Staff are braver about delivering sessions to people with dementia, they now feel more confident and try to make sessions more fun and engaging, they wouldn't have been as confident without the training (Manager)

In fact, several interviewees referred to the importance of building confidence, feeling this led to real change at the service delivery level:

It gave [me] confidence, to not be scared… [so we] thought about new things, like doing outside activities. We realised that we could look at this in future projects, the benefits of being out there (Staff member)

[We are] considering taking positive risks when developing services…seeing dementia as a framework, not just blocks of services… [We are] putting risks into context, there are risks for everyone, you could get run over by a bus (Manager)

This increase in confidence led to people living with dementia being offered services aimed at the general older population, moving away from the belief that targeted or specialist services were required:

It completely changed my perspective toward looking more holistically, [with] less of a focus on dementia, ways of providing better experiences to people with dementia, having a place that is friendly with everyone (Staff member)

The comments by many suggested that prior to the support provided through the programme, frontline staff (and volunteers) had preconceptions that services for people with a diagnosis of dementia were limited. More positively, the changes refer to a way of thinking that is more in tune with a SMoD, focusing on what the person can do. This is also reminiscent of the dementia friendly principle of taking an asset based, and avoiding a deficit, approach when organising and delivering services. In fact, for some, the need to move away from the idea that dementia should lead to a referral to specialist care, rather than offering general services was particularly important for an organisation such as Age UK, which needs to ensure it is providing support for all older people:

You don't have to provide specialist services, that is Age UKs unique selling point, providing generic services [you have] got to think about delivering a service that is suitable to all older people (Manager)

However, some interviewees identified particular challenges around providing more inclusive services. For some, the beliefs and attitudes of staff and volunteers, alongside existing service users, may be harder to maintain over the longer term. For example, reminiscent of Hare and Dean's (2015) findings, a few interviewees suggested that their commitment to offering more inclusive services was not always shared by colleagues, including senior staff. Further, whilst increasing awareness of existing staff and volunteers is one thing and can feasibly be supported through training and support (albeit taking into account resource considerations), extending this to the wider community presented more of a challenge. Interviewees reported that friends and family and care home and hospital staff could hinder progress due to holding specific views around what a person with dementia could feasibly do; an example was provided relating to a local day centre in one area:

The staff manager and clients of [our] current day services resist getting involved with people who have dementia; day service managers are protective of the atmosphere of current group of service users (Manager)

A few provided examples of where a person with dementia had exhibited behaviour considered unusual by other activity participants, such as being overfriendly. One interviewee mentioned that they were taking steps to shape the

attitudes of service users who may hold a view that people living with dementia should not be enabled to take part in a particular activity:

> If you have an existing group … and you want to make the group more inclusive, you have to start with the existing participants. They have to welcome the newcomers who may have dementia (Staff member)

Another issue, and one touched upon above when referring to the need to provide training and support, organisations essentially need to juggle finite resources, which for some impacted on the range of services that they could provide. In this vein, a few felt that the DF programme offer did not always fit with the strategic aims or priorities of their organisation:

> It was very useful but I felt some of it was idealistic, for example taking walks through parks is not our top priority at the moment (Manager)

> [The consultant] talked about accessible places in the lake district that stimulate memory, I feel perhaps other organisations may see this as priority, but we need to consider our own services, particularly the generic ones, so it didn't meet strategic aims (Manager)

The issue of funding further dementia-related work was raised by all interviewees, with many alluding to the paradox of securing funding for inclusive general services, arguing that local health and social care service commissioners were more likely to fund specialist services:

> The challenge is going to be finding the balance between not putting the label on [clients], but getting funding for it (Manager)

So whilst many interviewees reported that their organisation was looking to increase services for people living with dementia, there was still an issue around ensuring a range of inclusive services can potentially be offered. This was in part due to perceived attitudes of staff and others, but also due to limited resources.

Adopting a person-centred approach

Given the points made in the introductory section relating to the benefits of ensuring people living with dementia can continue participating in activities previously enjoyed, the reports that participating Age UK partners were beginning to move away from merely providing specialist services is an important one. Yet whilst both current and developing service provision showed positive moves in the right direction, it is nevertheless important that these are activities and services that people actually want. While the research team could not directly assess the programme's effect on the lives of people living with dementia, the methods and resources used by the consultants are all based on the principle that the voices of people living with dementia should be at the centre of making services more inclusive. The purpose of this is to shift the narrative away from more negative stereotypes and toward a focus on what a person with dementia can do. Indeed, initiatives such as DEEP support the benefits of this approach. Whilst there was no evidence that plans were necessarily in place to ensure service provision would be led by people with dementia, there were some promising examples of considerations around how this group would have more say in shaping services:

We are now doing much more consultation with service users, which we didn't do before, asking them what they think. It's a really good thing to do (Staff member)

Another interviewee suggested that their attitude toward people with dementia who approached services with a carer had now changed:

When advising someone with dementia, if a family member or carer is with them, we are clear on who our client is, who is asking for advice. If it is the person with dementia that person is our client and the other person is in a supportive role (Staff member)

Another interviewee who worked with people with advanced stages of dementia felt that they had become more mindful of the needs of their client group:

I now focus more on improving the person's quality of life rather than focusing on the incontinence. People with dementia have high rates of depression… so I'm trying to help improve mood by doing things they want to do. I did not previously look at it from this perspective (Staff member)

This quote makes the important point that though people in later stages of dementia may still not be offered the opportunity to get involved in some activities, staff nevertheless were reporting changes in the ways in which they looked to provide support to this group.

Other plans to ensure the voice of people living with dementia is heard, included:

- Organising regular client forums, done in a dementia-friendly way

- Organising focus groups that include people with dementia before new services are developed

- Involving people with dementia in environmental audits

Yet as it was not referred to by most, there is some way to go before services offered move towards being more person-centred. However, it is perhaps early days, particularly when it is considered that some interviewees referred to specific attitudes held before they took part in the intervention. It may be that greater provision of more inclusive services leads more organically to person-centred services for people with dementia.

Discussion

This paper has considered the role that frontline service delivery staff (both at a managerial and customer facing level), can play in developing more suitable services. It has shown that the way in which dementia is viewed and conceptualised can affect the way services are both designed and implemented. Overall the DF programme appeared to provide an effective way of raising awareness of dementia and dispelling some of the stereotypes that accompany the condition. Interviewees reported that it had influenced the mindset of some and led to changes in training and service provision. Communication, in various forms (both verbal and non-verbal) are viewed as important ways of conveying attitudes and beliefs. Whilst use of negative language was not discussed in detail, there were a few examples of where language was reframed, such as the organisation which changed the title of training so that it was more positively worded.

The findings demonstrate that programmes such as DF can lead to real, tangible change, particularly when we consider the examples where provision had been expanded to include people living with dementia who had previously been referred to day care or provided with indoor only support. The consultancy support, in particular, led to reported change in participating Age UK partners, with interviewees gaining confidence and understanding that people living with dementia can be enabled to access mainstream, as well as specialist services.

However, changing attitudes and beliefs more broadly, and offering and maintaining provision where other practical or immediate concerns may take precedence, was not without its challenges, and some interviewees referred to more critical elements of the programme. One challenge included adopting person-centredness in practice, such as those supported through initiatives such as DEEP. There was also an identified ethical tension between including people with dementia in general services, yet ensuring any support needs are met. Other concerns, such as ensuring the needs of other service users were met, was also discussed. There was also an ongoing reluctance, or the perceived inability of some, to support people with dementia in broader service provision. The difficulties around dealing with the attitudes and/or beliefs that other service users who do not have the condition may hold, were also important factors (as was that of the wider community). Sustaining the high level of training and ensuring that key staff continue to have the capacity to work towards becoming more dementia friendly beyond the lifetime of interventions was additionally assessed as an issue for some.

Whilst in the minority, some comments highlighted that organisations may feel unable to provide the types of services people living with dementia may want due to resource shortages. Furthermore, the importance of ensuring this group can

access mainstream services may have been fairly new for some, where it was felt that the basics (e.g. ensuring buildings are suitable) needed to be embedded before broader needs could be incorporated. Comments from two participants support this explanation: they felt that when they started to review and shape their services to become more dementia-friendly, they would not have been ready to look at outdoor activities. There is also a question around the scope of impact, such as based on assessed severity of dementia. We do not necessarily wish to comment on the suitability of services for people living with more advanced forms of dementia, but it does encourage thinking about dementia friendly services more generally, and what level of dementia these are aimed at.

Arguably, some of the changes factored into service provision, such as introducing colour to exercise sessions and using reminiscence boxes, whilst a positive step, do not necessarily challenge everyday practices or disrupt service users who are not keen to include people living with dementia. This latter point is perhaps one of the reasons organisations tended to cater more for those at earlier stages of the condition.

It is necessary to remember that there is more to a person living with dementia than a diagnosis, which is why ensuring services go beyond immediate practical and/or personal care needs is so important. In support of this point the findings identified that an intervention which looks to encourage a reframing of beliefs and attitudes, alongside awareness of the practicalities of service provision, is necessary. Giving regard to the philosophy behind the DF programme, and the apparent success of initiatives such as DEEP, we believe that ensuring services are person-centred should be viewed as a prerequisite to labelling it as truly dementia friendly. After all, people are unique and their daily living preferences, and indeed

coping mechanisms will be shaped by personal, cultural, social, political and economic and factors appropriate to the individual and their locality. For example, through asking people with dementia, DEEP have created guidance on the language that should be avoided so as to negate negative stereotypes (DEEP 2015).

Whilst the concept of dementia friendliness (and related concepts, such as dementia capable) is useful and important, if we are to ensure inclusion of people living with dementia at an individual, and/ or cultural level, perhaps a new focus is needed. As touched upon earlier, commentators such as Shakespeare (2017b) emphasise the need to be more rights focused, that we need to look at dementia enabling communities, 'we don't just need dementia friends, we need dementia allies' (2017, n.p). This point is taken up by Lin and Lewis (2015) who suggest the adoption of the concept dementia positive, defined as:

> Positivity towards dementia with an intentional emphasis on strength finding, manifesting through attitudes, beliefs, communication, and behaviors (Lin and Lewis 2015, 242)

For Lin and Lewis (2015) positive beliefs refers to the acceptance that someone with dementia is capable of living a meaningful life. They refer to the importance of ensuring changed attitudes and beliefs occur in tangent to observed behaviours. They view this as necessary to ensure well-being, and related to this, person-centredness, is truly maximised. They in fact express this view strongly:

> Without dementia positivity, regardless of how well the society provides resources, accommodations, services, activities, and opportunities for the person with

dementia and their families to stay engaged, it is merely a pseudo social inclusion

(Lin and Lewis 2015, 242)

It is important to add here that Lin and Lewis (2015) do not suggest that the principle of dementia positive should substitute dementia friendliness, but rather, that it should complement it.

Due to the nature of this paper, that of discussing beliefs, it is acknowledged that reported (or public) views, may not necessarily correspond to the private thoughts of individuals, which in some cases may lead to the actions of individuals being incommensurable to what they say (Kirkley et al. 2011). Of course, it is unrealistic to think we can resolve this issue, though it is perhaps reasonable to think that skills/training or suggested changes can lead to changed attitudes, which in turn lead to changed actions. Finally, it is important to note that the views of people living with dementia were not sought for this study. Whilst its aim was to focus on encouraging a broader range of dementia services, it nevertheless cannot be said with certainty what service users thought of the provision, or whether it was delivered as described.

This paper has considered the ways in which the beliefs and attitudes of frontline service staff may impact on services offered to people with dementia, using findings of an evaluation of a third sector led intervention, the DF programme, to aid discussion. Based on the literature and research findings, it is suggested that ensuring what is offered is person-centred is key; yet it is argued that culture will inevitably impinge on both the services offered, and the extent to which people with dementia will be consulted on service provision. Whilst exploratory, it is hoped that this paper can open up a new dialogue around the extent to which culture may impact on service provision and also to question what we mean by

dementia friendly, and whether additional concepts are required to support it. Without doubt this is a challenging endeavour, as beliefs and attitudes are harder to measure than tangible outcomes, such as adapted buildings, weekly activities or improved signage. Alongside this, there are broader concerns relating to the wider community, and securing funding to sustain levels of service provision and support. Overall, we suggest that use of an additional concept such as dementia positive, which has more of a focus on changing beliefs, may provide a useful way of ensuring that culture is considered alongside other, more physical changes that take place in dementia friendly communities. However, further reflection and debate around the need for a supplementary concept is needed.

Bibliography

Alzheimer's Society. 2018. "What is a Dementia Friendly Community." Accessed 3 September 2018: https://www.alzheimers.org.uk/get-involved/dementia-friendly-communities/what-dementia-friendly-community

Bantry-White, E. 2018. "Supporting Ethical Use of Electronic Monitoring for People Living with Dementia: Social Work's Role In Assessment, Decision-Making, And Review." Journal of Gerontological Social Work 0(0):1-19. doi:10.1080/01634372.2018.1433738.

Beattie, A., G., Daker-White, J., Gilliard and R. Means. 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 20 (1): 67–80 doi:10.1080/0968759042000283647.

Beck, W. L., M., Van der and A. Walker. 1997. The Social Quality of Europe. The Hague: Kluwer Law International.

Blackman, B. l., Mitchell, E., Burton, M., Jenks, M., Parsons, R., Raman and K. Williams. 2003. "The Accessibility of Public Spaces for People with Dementia: A new priority for the 'Open City'." Disability & Society 18 (3): 357-371. doi: 10.1080/0968759032000052914.

Crampton, J., J., Dean and R. Eley. 2012. AESOP Consortium: Creating a Dementia-Friendly York. York: Joseph Rowntree Foundation.

DEEP. 2018. "DEEP Guides." Accessed 21 August 2018. http://dementiavoices.org.uk/resources/deep-guides/

Department of Health. 2011. Start Active, Stay Active: A report on Physical Activity for Health from the Four Home Countries' Chief Medical Officers. London: Department of Health, Physical Activity, Health Improvement and Protection.

Department of Health. 2015. Prime Minister's Challenge on Dementia 2020. London: Crown Copyright.

Gov.UK. 2009, "Living Well with Dementia: A National Dementia Strategy." Accessed 4 April 2018. https://www.gov.uk/government/publications/living-well-with-dementia-a-national-dementia-strategy

Genoe, M. R., and S. L., Dupuis. 2011. "'I'm Just Like I Always Was': A Phenomenological Exploration of Leisure, Identity and Dementia." Leisure/Loisir 35(4):423-452. Doi:10.1080/14927713.2011.649111.

Hare, P., and J. Dean. 2015. "How Can We Make Our Cities Dementia Friendly? Sharing the Learning From Bradford and York, Joseph Rowntree Foundation, York." Accessed on 14 January 2018. www.jrf.org.uk/report/how-can-we-make-our-cities-dementia-friendly

Kirkley, C., C., Bamford and M. Poole. 2011. "The Impact of Organisational Culture on the Delivery of Person-Centred Care in Services Providing Respite Care

and Short Breaks for People With Dementia." Health and Social Care in the Community 9(4):438-48. doi: 10.1111/j.1365-2524.2011.00998.

LGA and Innovations in Dementia. 2014. *Dementia Friendly Communities: Guidance for Councils*. London: Local Government Association.

Lin, S.Y., and F. M. Lewis 2015. "Dementia Friendly, Dementia Capable, and Dementia Positive: Concepts to Prepare for the Future." The Gerontologist 55(2): 237–244. doi:10.1093%2Fgeront%2Fgnu122

Manthorpe, J., and K. Samsi. 2016. "Person-Centered Dementia Care: Current Perspectives." Clinical Interventions in Aging 11: 1733–1740. doi: 10.2147/CIA.S104618.

Menne, H. L., J.D., Johnson, C.J., Whitlatch and S.M. Schwartz. 2012. "Activity Preferences of Persons with Dementia, Activities." Adaptation & Aging 36(3):195-213. doi: 10.1080/01924788.2012.696234.

Mental Health Foundation. 2015. Dementia, Rights, and the Social Model of Disability: A New Direction for Policy and Practice? London: Mental Health Foundation.

Oliver, M. 2013. "The Social Model of Disability: Thirty Years on." Disability & Society 28(7): 1024-1026. doi:10.1080/09687599.2013.818773.

Oliver, M. 1983. Social Work with Disabled People. Basingstoke: Macmillan.

Perkins, R. L., Hill, S., Daley, S., Chappell, M., and J. Rennison. 2016. "Continuing to be Me: Recovering a Life with a Diagnosis of Dementia." ImROC: Nottingham.

Robinson, L., D., Hutchings, L., Corner, T., Finch, J., Hughes, K., Brittain, K., and J. Bond. 2007. "Balancing Rights and Risks: Conflicting Perspectives in the Management of Wandering in Dementia" Health, Risk & Society 9 (4): 389-406. doi: 10.1080/13698570701612774.

Shakespeare, T. 2006. "The Social Model of Disability." Chap. 16 in The Disability Studies Reader, edited by Davis, L.J. New York: Routledge.

Shakespeare, T. 2017a. "Why Viewing Dementia as a Disability Could be Helpful to Everyone, Dementia Without Walls." Accessed 11 October 2017. http://dementiawithoutwalls.org.uk/2017/05/why-viewing-dementia-as-a-disability-could-be-helpful-to-everyone/

Shakespeare, T. 2017b, A Point of View BBC Radio 4.

Swaffer, K. 2015. "Dementia and Prescribed Disengagement" Dementia 14(1): 3–6. Doi: 10.1177/1471301214548136.

The Care Act. 2014. The Care Act. London: The stationary Office.

Thomas, T., and C. Milligan. 2017. "Dementia, Disability Rights and Disablism: Understanding the Social Position of People Living with Dementia." Disability & Society 33 (1):115-131. doi: 0.1080/09687599.2017.1379952.

Thomas, T., and C. Milligan. 2015. How Can and Should UK Society Adjust to Dementia? York: Joseph Rowntree Foundation.

World Health Organization and Alzheimer's Disease International. 2012. "Dementia: A public health priority" Accessed 14 January 2018. http://apps.who.int/iris/bitstream/10665/75263/1/9789241564458_eng.pdf?ua=1