Title: Business engagement in a civil society: Transitioning towards a dementia-friendly visitor economy

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Abstract

Dementia is a growing global health condition primarily, though not exclusively, associated with ageing populations. This paper examines dementia awareness and the perspectives of businesses and organisations in the visitor economy, given that people with the early stages of dementia remain consumers of leisure and tourism experiences. It adopts the concept of the civil society where people are treated in a fair and equitable manner irrespective of their abilities and state of health to promote equality of opportunity. As an exploratory study, it evaluates the awareness, perception and experience of businesses in developing a dementia-friendly visitor economy. It focuses on dementia as a 'hidden condition' with a focus on the attractions sector to develop a greater understanding of how to embrace dementia as part of a civil society. The research highlights the implications for the wider visitor economy with dementia set to grow globally in scale and significance.

Keywords

Dementia Visitor economy Alzheimer's disease Business engagement Civil society

Business engagement in a civil society: Transitioning towards a dementia-friendly visitor economy

1.0 Introduction

Globally, there is an increasing trend within both developed and developing countries to acknowledge the importance of how to achieve the objectives of a civil society, where the interests and needs of citizens/communities are met in a fair and harmonious manner. Governments often set out such ambitions to guide institutions and stakeholders (e.g. the third sector and businesses) towards collaborative ways to achieve these objectives (Covey & Brown, 2001). The idea of the civil society, predominantly a European notion associated with citizenship (e.g. see Ferguson's 1787 treatise and discussion by political commentators such as Marx and Gramsci), is much contested in the social sciences. In the post-war period, much of the debate around the civil society was espoused in liberalism around the rights of the individual and growing people power, marked by key studies such as Marshall (1964) which highlighted the citizenship concept in the civil society debate. The 1960s also saw thinking around the civil society paradigm shift in focus towards the rights of the individual, particularly the passive and active ways in which individuals and the organisations they work within fulfil their rights and obligations in society. While some of these debates remain philosophical, theoretical and highly politicised (see DeLue & Dale, 2016), the application of civil society concepts across a range of social, cultural, religious, political and other divisions remains of global relevance (Birks, 2014).

Despite a recent resurgence in the popularity of the concept (see Keane, 1998), one neglected dimension in the lexicon of the civil society is the role of businesses and how they can be engaged by governments and NGOs to achieve civil society ambitions. In particular, the idea of addressing inequality of groups within society that may be excluded from full participation (such as the elderly) is of increasing interest to businesses seeking to extend their market reach. The marketing literature (e.g. Gronroos, 2011) posits that such groups represent a market for development through value creation processes, as evidenced in the Barclays (2015) report on the hidden nature of consumer spending amongst an ageing population. The report found that 20% of the hospitality businesses in the UK derived their turnover from those aged over 65, yet only 5% of businesses saw this as an important market. Conversely, civil society ideals reject segmentation based on social difference. As Hall (1995) argues, one premise of the civil society necessitates escaping cages and to value the individual for their own worth and contribution rather than focusing on social divisions and subsequent tags.

For businesses with a primary focus on profit, there is a growing academic discourse within several literatures including business ethics, corporate social responsibility and social capital on how businesses engage with the objectives of a civil society. One strand of this debate focuses on potential gains in competitive advantage and market penetration where latent demand exists. A second related strand concerns how businesses adapt and innovate, given new agendas and issues. These diverse agendas spanning the business and management literature, in which tourism is embedded, as well as debates in sociology around inclusion/exclusion and the civil society, provide a germane interdisciplinary area of study to advance thinking on the role of tourism and the visitor economy[i] in such discourses. Accordingly, there is a need to look at the interdisciplinary intersection of business behaviour, social groups and customers who may be excluded from existing service business activity.

This paper is an innovative contribution to the developing literature on one emergent dimension of engaging excluded groups within a service setting: people with dementia and their carers. It is the first academic study undertaken to date which examines the degree of business engagement with a growing societal health condition (i.e. dementia). Dementia is acknowledged as a condition that leads to disability (United Kingdom Government, 2016) but it is not defined as a disability *per se*. Whilst there is a well-developed research literature on disability and its implications for tourism and leisure accessibility, this paper focuses on dementia as a 'hidden condition' in much the same way that autism has been approached as a less visible mental condition (see Hamed, 2013 for an example which identifies some similarities with the problems people with dementia face when travelling in relation to sensory demands, stereotyped behaviour, changes to routine, communication challenges, sleeping problems and coping with associated medical conditions). The issue of accessibility for people with dementia drawing upon the lessons of the disability and social inclusion literature is discussed in other papers (e.g. see Genoe (2010) and Innes, Page & Cutler (2016) on leisure and Page, Innes and Cutler (2015) on dementia-friendly tourism) and is not reiterated here. Whilst it is acknowledged that there have been many fruitful lines of inquiry around social attitudes towards disability (e.g. see Daruwalla & Darcy 2005) and other embodiments of disability (see Oliver, 1996; Imrie & Hall, 2001; Preiser & Ostroff, 2001), the focus of this paper is on dementia as a hidden medical condition rather than as a disability.

The findings of this study have international implications given that the number of people with dementia is forecast to expand exponentially in many countries, as an ageing population structure continues to grow and the condition becomes more prevalent. In this respect, whilst this study draws largely from evidence in the UK, it has global policy and management implications as dementia becomes more visible issue on political and health agendas of both developed and developing countries. Within the scope of tourism and leisure in a civil society, dementia is creating

a group of consumers who are not able to participate fully for two reasons: the nature of the condition; and existing scope of service provision. It is the latter on which this paper focuses.

Paradoxically, many people with dementia (and their carers) are from the *baby boomer* generation in the UK and other western nations (i.e. born between 1946 and 1964) that benefitted from the post-war boom in holiday-taking, comprising a social group used to leisure-related consumerism. For service businesses to cater for those with dementia within mainstream provision, a better understanding of the condition including recognition of its symptoms and adjustments that facilitate participation is needed. This resembles the discourse and actions around disability and accessibility that became more integrated into thinking in the visitor economy during the 1990s. In some countries, legislation is in place to ensure access to all and dementia is no exception to this (for example, the Equality Act 2010 in the UK). However, as stressed earlier, dementia is not considered a disability *per se* (although is a major contributor to disability in the elderly) (World Health Organization (WHO), 2012). Dementia is a progressive brain disease that is incurable and creates disability when it has a long-term effect on day-to-day life, and it is recognised as a disability in law in many countries, the spectrum of the condition is very wide.

As Lin & Lewis (2015, p. 242) recognise, "parallel efforts can be made to help people with dementia and their families integrate into the society at large", thus advocating the civil society concept. Whilst acknowledging the significant body of literature and knowledge developed over the last 30 years on disability and accessibility in tourism, this paper adopts an anti-disablist approach that focuses on the individual which, as Thomas & Milligan (2015) suggest, might challenge conventional thinking on disability, and which advocates personhood (Kitwood, 1997) and active citizenship (Brannelly, 2016) as a key strand of the civil society concept. Thomas & Milligan (2015) argue that since the 1990s, an increasing number of conditions have acquired disabled status in law and while this is a positive move for people requiring support, it has created an increasingly large oppressed group, often marginalising them socially. Therefore, this study pushes the boundaries of knowledge by developing and reviewing a model of how businesses interact and engage with the issue of dementia in their customer-facing activities. Our underlying rationale for such a study is to understand how businesses can contribute to encouraging people to *live well* with dementia in a more inclusive, civil society predicated on active citizenship and participation in society through the removal of barriers and discrimination.

The UK has been chosen as the location for the study because it is widely accepted amongst policymakers internationally as the leader in thinking in this domain, with high level action to create a fairer and just society for people with dementia (see, for example, WHO, 2015). The Prime

Minister's Dementia Challenge, as one example, has set ambitious targets to train 1 million people to be 'dementia friends'[ii] to raise awareness and understanding of dementia in communities. A core strand of that challenge is to encourage businesses to become dementia-friendly (DF) (other terms frequently used interchangeably include dementia capable, memory aware and dementia aware). This is the first exploratory study to scope and evaluate the implications of such a strategy for businesses within a service context, namely the visitor economy. Using a case study of Scotland's visitor attraction sector, this paper utilises two sources of primary data to assess how one sector perceives the dementia challenge and their attitudes towards this emergent policy agenda. As an exploratory study, the paper utilises a case study approach to combine a small-scale quantitative survey and qualitative data derived from in-depth interviews to assess the awareness, actions and challenges within the public and private sector visitor attraction sector of becoming more DF.

The paper commences with a brief discussion of the significance of dementia as a growing international health condition and the policy discourses around the theme along with the objectives of developing DF communities and the implications for businesses. The paper then examines the methodological issues associated with the study and then moves on to examine the findings and analysis. The implications for the management of business activity in relation to the visitor economy are discussed along with the wider issues for other countries, followed by the conclusion.

2.0 Dementia and building dementia-friendly communities

Dementia has emerged as a global health condition affecting developed and developing countries, and Alzheimer's Disease International (2015) estimates that in 2015 there were around 46.8 million people worldwide living with dementia. This study suggests that the number of cases will double every 20 years, so that by 2030 there will be around 74.7 million cases, rising to 131.5 million by 2050. Dementia is an issue of global importance as indicated by the geographical extent of studies and the international proliferation of organisations set up to engage in and fund research, promote understanding of the disease and provide support to those affected by it. Unlike some conditions of the modern world exacerbated by sedentary and unhealthy lifestyles, dementia is boundary-free, affecting both developed and developing worlds. Under the auspices of the term 'dementia' are in the region of 160 conditions, the best known of which is Alzheimer's disease, and typified by a progressive cognitive degeneration based on three broad stages: early, mid and late stage along a time continuum of mild to severe symptoms. Dementia is a disease of the brain, not a mental health condition. In the UK, dementia has recently assumed a greater public significance since the Office for National Statistics (BBC, 2016) indicated that dementia (including Alzheimer's disease) had supplanted heart disease as the leading cause of death in England and Wales accounting for 61,000 deaths equivalent to 11.6% of all recorded deaths. The focus of this paper is on the early stage of

the disease, when independent living can be maintained but where symptoms connected with cognitive loss may start to interfere with daily life, work and social activities (Steeman, De Casterle, Godderis & Grypdonck, 2006). Dementia encompasses a complex range of symptoms including difficulties with memory, logic, language, and ability to perform everyday tasks, the scope of which extend beyond the remit of this paper but can be read in more depth in publications such as WHO (2012).

2.1 Living Well with Dementia

The prevailing consensus on the long-term care of people with dementia is maintaining independence to *live well*. Within the realm of dementia policy and practice, 'is it possible to live well with dementia?' is a frequently posed question. One of the aspects of living well is the freedom to go on holiday and enjoy leisure time within the constraints imposed by dementia, particularly at the early stage. As Watson (2016, p. 5) states: "part of living well with dementia is having fun, in whatever form that takes". Genoe & Dupuis (2014) identified that one way of living with dementia is to maintain participation in meaningful activity, and initiatives that provide stimulating leisure and recreational experiences for people affected by dementia are now quite well established, particularly in the arts and culture arena. Research has shown that individuals with early stages of dementia value outdoor recreation, which provides opportunities for exercise and enjoyment of the countryside. Furthermore, the positive impact on emotional well-being appears to reduce the effect of dementia with both the frequency of outdoor activity and the range of areas visited (Duggan, Blackman, Martyr & Van Schaik, 2008). Paradoxically, increased periods confined to the home not only reduce opportunities for social and environmental encounters that stimulate well-being but increase feelings of depression. Consequently, being able to continue with a range of activities undertaken prior to diagnosis can help people living with dementia to maintain quality of life as far as possible and even mitigate against more rapid deterioration and care intervention. This also has financial benefits for many stretched health systems, helping people to live at home for longer.

Roland & Chappell's (2015) study on meaningful activity for people with dementia from a caregiver's perspective emphasises the opportunities in the early stage of the condition. Being able to go out, interact socially and spend quality time with a partner in a mutually enjoyable pursuit (e.g. on holiday to help stimulate memories of places visited) is particularly valued. Furthermore, Roland & Chappell (2015) emphasised the importance of keeping a sense of normality for those with a dementia diagnosis, often highlighted by engaging in activities they used to enjoy and keeping interested in the world around them, yield social benefits and self-worth. For some, the idea of 'doing things while they can' highlights an added aspect of where tourism and leisure experiences can play an important role. However, the reality is that many people with dementia find it difficult to

take part in activities that they once enjoyed (Alzheimer's Society, 2013), and the critical aspect in this is whether the service sector can engage more fully to reduce the barriers from a supply side perspective. To facilitate such meaningful activity as part of a civil society, policy research indicates that DF needs to be embedded into our communities and business activity. One important development is the creation of Dementia Friendly Communities (DFCs).

2.2 Creating Dementia-Friendly Communities: *What are they?*

While DFCs are positioned "at the forefront of the policy agenda" (Alzheimer's Society/BIS, 2015, p. v), with the aim of establishing and enabling an inclusive locale where people with dementia feel empowered, safe, have access to services, social networks and meaningful activities which require the involvement of the business community. Essentially, this concerns the development of a caring community that supports and accepts social difference (Thomas & Milligan, 2015). The Local Government Association (LGA) (2012) and other studies have sought to clarify what a DFC (see Figure 1) means.

Figure 1 here

In the UK, around 850,000 people are affected by dementia, 90,000 of whom live in Scotland (3,200 of whom are under 65 years of age) (Alzheimer Scotland, 2016). In Scotland, the number of people with dementia is expected to double by 2031 (Scottish Government, 2013) and *Scotland's National Dementia Strategy 2013-16* reaffirms the importance of enabling people to live independently. Estimates show that around two-thirds of people with dementia live at home, with the Alzheimer Society *Dementia 2014* survey finding 40 per cent felt lonely and 32 per cent did not feel part of their community. By 2015, 82 communities were signed up to the Alzheimer Society DFC recognition process[iii] in England and Scotland embodied in many pioneering projects such as Motherwell becoming a DF town centre in 2012 supported by the work of Alzheimer Scotland. Glasgow City, with an estimated 8,000 people living with dementia, is currently consulting on becoming a DFC. Awareness of dementia in Scotland among the general population was examined in the Scottish Social Attitude Survey in 2014 (Reid, Waterton & Wild, 2015), with 76 per cent of respondents aware of people with, or families affected by, dementia.

As Crampton, Dean & Eley (2012) indicate, individuals are consumers prior to the onset of dementia and remain as consumers and users of businesses and services after diagnosis, particularly so in the early stages of the disease. In this respect, nothing changes. However, the role of business engagement in this process remains poorly understood empirically and conceptually, with evidence from large corporations (e.g. Lloyds Bank and their Tea and Talk events in its 1,600 UK branches) and individual initiatives being limited mainly to ad hoc assessments. Yet as Crampton and Eley (2013, p.

49) argue, 'the concept of dementia-friendliness is not the exclusive domain of the health and social care world… it is the daily attrition of everyday life where help is most needed. People with dementia and family carers find routine activities most difficult – shopping, managing finances, using transport, keeping active – causing them to withdraw and impacting upon their well-being'. Therefore, this paper seeks to address the research problem of *how can we understand the barriers to, and encourage adoption of, DF measures amongst businesses in the visitor economy?*

Several aspects of DF practice relate specifically to the service business environment, such as the existence of "respectful and responsive businesses and services" (Department of Health, 2015, p. 10), where staff understand and recognise symptoms of dementia as displayed by customers. In terms of a civil society, this is predicated on mediating institutions that operate within four spheres in society (Janoski, 1998; Edwards, 2009): *the private market*; *the public sphere* (in which the third sector or charitable sector exists; *the state* (i.e. which sets the legislative framework) and the *private sphere* (in which family, friends and community associations exist). In this paper, the private market is the focus of this paper given the dominance of small-medium sized private businesses in the tourism sector, and the relative speed with which DF practices are expected to be incorporated. The PM Challenge (Department of Health, 2015) sets out that all businesses should be encouraged to become DF by 2020 and that industry sectors should have DF charters to guide best practice. In a tourism and leisure context, this is important given that facilitating enjoyable and meaningful experiences through service interventions might contribute to quality of life and well-being, which in turn might prolong independence and an ability to remain living at home. While respite care is a well-established form of holiday break for people living with dementia and their carer(s) (Weightman, 1999; Kirkley, Bamford, Poole, Arkey, Hughes & Bond, 2011), this paper seeks to provide a new contribution to knowledge and practice with a focus on businesses working outside of the respite sector - those who cater for all customers in the visitor economy.

Watson (2016, p. 5) highlights that some people are "reluctant to embrace" DF practices. Despite high profile media coverage, celebrity endorsements of the 'cause' and an increasing acceptance of dementia as part of our society, lack of awareness and, perhaps worse still, stigma about "the D-word" (Milne, 2010), there is a need to permeate the development of DF actions in mainstream society and outside of the medical and care communities. The World Health Organisation (2012) has highlighted this issue as one that must change so society becomes more DF (similar to increased awareness of cancer) as part of a civil society.

2.3 Business transition towards dementia-friendly environments: operationalising the concept

There is a well-established frame of reference on making environments DF, including a large literature and practical guidance on establishing DFCs (e.g. Alzheimer's Society/BSI, 2015; Crampton,

Dean & Eley, 2012; Local Government Association, 2012). Specific environments that have been examined include: *health care environments* care homes, clinics and hospitals (e.g. Waller, Masterson & Evans, 2016; Davis, Byers, Nay & Koch, 2009; Marquardt & Schmieg, 2009) although there is less literature non-institutional environments. For example, studies have examined *the home* (e.g. Zabalegui et al. 2014); *age-friendly cities* (e.g. Buffel and Phillipson 2012); *age-friendly banking* (e.g. Lock, 2016); *eating out/the hospitality sector* (e.g. Cassolato et al. 2010); *memory cafes* (e.g. Morrissey, 2006); *outdoor environments* (e.g. Brittain, Corner, Robinson & Bond, 2010; Mitchell et al. 2013; Phillips, Walford, Foreman, Hockey & Lewis, 2013); *faith communities* (e.g. Plunkett and Chen 2015); *museums and art galleries* (e.g. Eekelaar, Camic and Springham, 2012; McGuigan, Legget & Horsburgh, 2015; Selberg, 2015); and *cinema attendance* (e.g. Batt et al., 2014).

This work demonstrates that a body of cross-disciplinary knowledge is slowly emerging about the needs of an ageing population and their interactions with the service environment, and those who are living with dementia. How and why businesses choose to become DF is associated essentially with the notion of business adoption of ideas and innovations to tailor their services to customer trends. Business support has developed mainly through the work of dementia organisations, notably the pioneering role of the Alzheimer's Society in producing guides for businesses and customer-facing staff (see Alzheimer's Society, 2015, n.d). Conversion of these ideas is gradually emerging within the tourism context, for businesses (National Coastal Tourism Academy (NCTA), n.d.), although guidance for those going on holiday is more readily available (e.g. Alzheimer's Society, 2016).

To understand the concept of business adoption and how new ideas such as DF are embraced, several fields of study help to inform thinking. For example, in the health and social care literature, the growth in awareness of the notion of people with disabilities as well as research in the period since the 1990s illustrate some of the reasons why businesses have voluntarily adopted measures to embrace disability. This includes: as *a market segment* (i.e. economic reasons); for *altruistic reasons* (e.g. to achieve corporate social responsibility goals (see Segovia–San–Vuan, Saavedra & Fernández-de-Tejada, in press); and in response to *regulatory measures* (e.g. disability legislation and the UK Equality Act 2010). As emphasised earlier, dementia is not a disability but the way businesses respond to disability illustrates a wide mixture of approaches to enabling accessibility. This literature combined with the generic business and management literature on the adaption of innovations (e.g. technology) and the business model innovation literature (e.g. Amit and Zott, 2012) suggest that there are distinct stages in how businesses adopt and engage with innovation or new ideas. In the case of the UK, the DF paradigm is very much predicated on a model of innovation diffusion (as discussed below around dementia champions), where spillover benefits of early adopters create a locality or industry sector model to permeate DF within the business area.

However, these models are very much business focused at the micro level and do not embrace the wider notion of moving towards a civil society and the challenge of developing DF experiences. Therefore, in this paper we present a model which has its roots in the WHO (2012) *Dementia: A Public Health Priority* report, which focuses on how to integrate dementia into a civil society and the stages a society may pass through en route to becoming DF. We have modified this model, as shown in Figure 2, to create a conceptual basis upon which to explore whether businesses in the visitor economy fit with the predicted phases of adoption and development of DF services and products for businesses. The model outlined in Figure 2 has been redesigned from the initial phased approach by WHO towards developing a DF society. In the case of businesses, we have adapted the model to critically evaluate the challenges in each stage of business transition towards becoming more DF. Whilst any model is a simplification of reality, one of the objectives of this study was to assess the validity of this model and whether it adequately reflects the transitioning process. We are cognisant that such a model reflects the management and innovative capabilities of businesses and recognition of the benefits of change to their bottom line as well as other motivations such as being an ethical business and having a commitment to corporate social responsibility.

Figure 2 here

Furthermore, Hollenstein (2004) identified five major barriers to adoption, in the case of new technology, that helps to explain the absorptive capacity or reluctance of individual businesses and their attitudes towards changing business practices as outlined in Figure 3. Therefore, resistance and motivation are key drivers in adapting the new technology adoption model to DF settings for business, often with the list of barriers exceeding the list of perceived benefits which may be associated with the culture within business, the leadership and organisational predisposition to innovation. Whilst this paper is not about innovation *per se*, theoretical explanations of how innovative ideas are embraced within and between organisations is helpful in underpinning this model. Much of the current thinking around developing DF communities in the UK (associated with Dementia Action Alliances in England) is predicated on the epidemic model of diffusion of the idea (see Beltrami, 1993). Such a model is particularly well suited to the voluntary adoption of DF within a prescribed timeframe (i.e. by 2020), since the idea is spread initially by dementia champions at different levels within a civil society to enact change from the Prime Minister's Working Group down to regions and local communities to promote the development of DF communities. These champions have tended to be the leaders of change who are persuasive, risk takers and have sought on a limited basis to engage with businesses to sustain innovation in this area. However, the role for businesses centres on voluntary adoption, despite the legal requirements on accessibility for all services as enshrined in the UK by the 2010 Equality Act. With these issues in mind, attention now turns to the methodology developed for this study.

Figure 3 here

3.0 Study methodology

This exploratory study aimed to evaluate the awareness, perception and experience of businesses in the context of developing a dementia-friendly visitor economy. The study was located in Scotland, UK, given the triple perspective of: the country's high occurrence of dementia, where three quarters of the respondents in a 2014 survey of dementia awareness in Scotland were affected by it in some way (Reid et al., 2015); the presence of progressive policies on dementia awareness and care; and, the prominence of the visitor economy. The objectives of the empirical research were to: assess levels of dementia awareness among businesses operating in the visitor economy; evaluate the perceptions and experiences of businesses towards becoming DF; identify adaptations that businesses have already made to accommodate customers living with dementia; and, understand the resource needs of businesses seeking to become DF.

The study adopted a two-stage sequential mixed methods approach within the pragmatic research paradigm. Given dementia and the visitor economy is a new concern within several literatures (for example: tourism, leisure, dementia, wellbeing, health), this approach provided the flexibility to identify and explore in more depth what is happening at the current time and how best to understand (Creswell, 2009) the challenges of dementia for service businesses in accommodating a more DF approach. First, a survey of service businesses in the visitor economy was designed, with an online questionnaire launched in partnership with a trade association. Second, a series of in-depth interviews were undertaken with a wider audience of tourism organisations, visitor attractions and dementia services. For the purposes of this project, it was decided to focus on visitor attractions and venues for day trips that are used by both day visitors and tourists. This was based on the knowledge that local residents act as an important market for visitor attractions (Leask, 2010; Connell, Page and Meyer, 2015), and that people living with dementia seek venues where they can enjoy quality leisure experiences, and in fact might form a larger component of the market as compared with those staying away from home on holiday[iv]. Given that attractions act as a focal point of interest for local residents, day visitors from outside the local area and tourists, the sector provides a useful test bed to explore how the visitor economy approaches the wellbeing of visitors with dementia and what strategic and operational opportunities, issues and barriers exist.

3.1 Survey

The first stage process encompassed a small-scale questionnaire online survey of visitor attractions distributed to the membership of a national trade organisation. Acknowledging the potentially sensitive nature of the topic, where some respondents may have personal experience of dementia,

participants were informed any questions with which they felt uncomfortable could be left blank, and that they could withdraw at any time. Furthermore, IP addresses were not recorded and participant anonymity was assured. The survey was designed to collect the aggregate perspective rather than the identity of individuals. The survey was approved by a dementia research specialist to overcome any potentially offensive or challenging wording or content, and was approved through a University ethics process.

The survey was made available via a link on the trade organisation website, with emails sent direct to 450 businesses. Two reminders were sent, one after 2 weeks and a final one after 4 weeks, yielding 31 responses (7% of the total membership). While this is a very low response rate (a common theme being reported in some areas of business and management research – see Mellahi and Harris, 2016), and the results cannot be used to generate reliable statistics, it does indicate that businesses may not view the topic as important, or that it is an uncomfortable issue which people would rather not contemplate. This is an interesting finding which we will return to later in the paper. Despite this drawback, the questionnaire assisted in identifying pertinent issues that could be examined in more detail through the second stage qualitative approach to understand more fully and to explore gaps in our understanding. The low response appears to reflect the experiences of a disability audit commissioned by the Department of Work and Pensions (DWP) in 2014, where only 4% of 105 national retailers and 5% of 58 UK restaurant chains responded to a request for information (DWP/DisabledGo, 2014). Lack of response might be related to the stigma surrounding dementia (Milne 2010) and fear of the condition (Kim et al., 2015), a somewhat "taboo subject" (Scott, 2001).

3.2 Interviews

The second stage of the research process focused on a series of semi-structured interviews with industry leaders and key service providers. An interview schedule was drawn up to extend some of the ideas in the questionnaire to facilitate a deeper investigation of tourism business awareness and attitudes towards DF initiatives. The central tenet of the interviews was to garner insights from a range of stakeholders, including: those who are already involved or those who have an interest in developing DF ideas within a service environment; those who have a strategic/policy overview in the sector; and those who have more specialist knowledge of DF environments. A sample of respondents were selected using the key informant technique to identify a range of key businesses, service providers and organisations within the sector, which was extended through snowballing procedures. Twenty interviews were undertaken by telephone, and these were audio-recorded, and transcribed. Interview length ranged between 30-60 minutes, reflecting both the sensitivity and newness of the topic, and to some extent, the limited awareness and activity in DF initiatives. While

the question schedule acted as a structure for the initial thematic analysis, an emergent thematic approach was adopted to construct sub-themes and codes, using Nvivo.

The coding process comprised several in-depth readings of each transcript, and grouping of key issues as advocated by Ritchie & Lewis (2003). Transcripts were subject to open coding organised around the six stage conceptual framework to identify a substantive range of issues that emerged from the interviews, and based around a priori and emergent themes. Axial coding to refine groupings of issues in relation to interview narratives, and confirm relationships between categories was then applied to highlight the primary issues. Selective coding was then applied to look for patterns in the data and possible connections between responses (see Corbin & Strauss, 2014).

The analysis took a typology approach that cuts across the interviews and survey (see White, Woodfield, Ritchie and Ormston, 2014) using the stages in the civil society model (Figure 1). Given the small number of survey responses, the survey findings are mixed with the qualitative analysis to explore themes. Short quotes from interviews are embedded within the text to provide evidence of themes and represent a range of views, as advocated by Creswell (2013) and Merriam (2009), which address the six stages of the model and illustrate the views of participants and the variety of responses towards dementia as it relates to the visitor economy.

4.0 Findings and Analysis

The analysis is based on the conceptual framework offered by the civil society perspective developed by WHO (2012) and subsequently adapted by the authors. The key premise here is that as society progresses through the different stages, the principles of a civil society will be achieved ultimately where people with dementia will be treated in a fair and non-exclusionary manner, reinforcing our philosophical stance based on an anti-disablist approach that focuses on the individual. This conceptual framework offers six categories across a time spectrum that conceptualises the stages of awareness and acceptance of dementia within a civil society, and how businesses might respond at each stage (Figure 2), as follows.

4.1 Stage 1: Ignoring the Problem

The interviews present little evidence of dementia being ignored. To the contrary, few businesses indicate this underlies any lack of provision from their perspective. While just under two-thirds of businesses in the survey had not yet considered DF initiatives in their business operations, all businesses disagreed with the statement ‘I am not interested in DF initiatives’ (24 of 31 businesses

strongly disagreed with this statement)', while only two agreed that dementia is 'irrelevant for tourism businesses'. Some 27 of 31 agreed that developing DF initiatives 'is important for the tourism industry', 17 strongly agreeing. The central factor associated with overlooking dementia centred on a lack of awareness.

4.1.1 'Not on the radar'

A strong theme that emerged from the interviews is that the topic of dementia had simply not *"come up"* within the business context. This is apparent in a lack of awareness and knowledge about dementia and how to engage, as one participant noted: *"…there's probably a lot of untapped potential that people don't really…know about…"*. As such, the issue is not that businesses are ignoring or do not want to engage with dementia but that the topic is simply not on the radar, and that *"… a lot of attractions are missing an opportunity at the moment"*. Some responses mentioned low public awareness in general, while another view was that if dementia is something for businesses to become active in, then the stimulus had not yet emerged: *"I haven't had anyone approach me…regarding becoming dementia friendly…it doesn't seem to be something …that people are really actively talking about"*.

Where health/disability organisations had been active in working with businesses in a more general way people with disabilities or special needs are more widely cited. In particular, autism was mentioned several times where initiatives had been put in place in attractions, particularly for children. A challenge for dementia as one interviewee hesitantly mentioned is the stigma attached, where *"…I hate to say this, but dementia is quite…unattractive…"* and the inherent difficulty in encouraging businesses to engage in a topic shunned by many given the stereotypical images of people in the later stage of the disease and as discussed by Kim, Sargent-Cox & Anstey (2015), fear of the disease. There is a view overall that dementia awareness is *"…maybe…not filtering down to everybody…"*, and for those businesses, people with dementia are *"not…a target area that we've ever identified…"*. These issues are developed further as demonstrated in Table 1.

Table 1 here

4.2 Stage 2: Some Awareness

One of the objectives of the study was to appraise the level of awareness of dementia. In the survey, responses on dementia awareness demonstrated a reasonably good level overall compared with questions run in similar surveys (e.g. Scottish Government, 2010). Just under two-thirds of respondents correctly defined dementia as a brain disease, as opposed to a mental health condition or part of the normal ageing process, while the same number had heard of the term DF. In terms of how likely people with dementia would engage in certain leisure activities, the majority of

respondents recognised that people with dementia engaged in activities such as eating out and going on holiday (see Table 2), thus refuting the stereotyped image of the late stage of the disease.

Table 2 here

However, given the opportunity to probe more in the interviews, definitions of dementia commonly demonstrated a limited understanding of the disease, often acknowledged as so by the respondent (Table 3).

Table 3 here

While 20 of the 31 (65%) businesses surveyed had heard of the term DF, the level of understanding of the meaning of the term was much lower. Only one business said they were 'extremely aware' of what DF means, while seven said they were 'not at all aware'. The interviews were able to explore awareness in much greater depth and to evaluate how awareness develops, and how it is applied in a business context. A significant amount of interview narrative was assigned to the 'some awareness' category, which reflects each participant's ability to talk about their own personal understanding and reflections on dementia awareness in an organisational perspective. These issues are further extended in subsequent categories (see Appendix 1 for more detail) which appear to be key influences.

What emerges from the research is that one member of staff can stimulate interest and action within an organisation, for example, one business had a staff member who had previously worked for a dementia organisation so their *"consciousness level is a maybe a bit up"* on others. As Table 7 shows, most businesses demonstrate a positive attitude to introducing supporting initiatives for people with dementia, but there is a general concern among most businesses about knowing what to do and as a consequence, appropriate support is required: "*we definitely go above and beyond the things that we have to do legally so for us it would probably be quite easy to put in some new things…*". One view is that when "*something becomes the next big thing*" audiences grow and provision develops into something provided as standard, e.g. sign language tours or tactile objects for visitors with visual impairments.

In terms of knowledge of campaigns to raise awareness of dementia, this was strongest for specific local initiatives, but minimal with respect to national initiatives and dementia organisations. Where recognition exists, it was due to either personal or organisational connections, or where there were specific initiatives in place (e.g. accessibility codes, advisory panels and partnerships with dementia groups). However, this is sporadic and not uniform in application, indicating a need to understand the nature, scope and effectiveness of infrastructure underpinning dementia awareness.

4.3 Stage 3: Building Infrastructure

Given a variation in levels of awareness, the next stage assesses the extent to which infrastructure is being developed, promoted and engaged with to promote dementia awareness and action within the visitor economy. This was the most extensive area of narrative within the interview data, producing 16 codes, which were reduced through axial coding and selective coding to four heavily inter-related themes:

4.3.1 Business engagement and training

A theme reiterated from Stage 1 is lack of action due to lack of knowledge, as typified in the comment: *"…we don't necessarily have the knowledge…to know what else we could do to help…"*. Business owners, managers and individuals within organisations who have a relatively low level of awareness are unlikely to take actions simply because they have insufficient knowledge. In addition, some are coming into contact with dementia in their business settings: *"…we come across it [dementia] quite regularly, so we have had a variety of situations…and we've done our dementia training for quite a number of years now"* and further evidence of these issues is shown in Table 4. As Table 4 shows, the primary concerns are lack of information, lack of knowledge and awareness: not having the necessary knowledge to develop DF facilities or make adaptations. However, barriers to training mostly relate to cost and resource issues.

Table 4 here

4.3.2 Resources

Appendix 2 illustrates, in detail, the primary negative and positive aspects relating to resource issues within visitor economy businesses and organisations. The clear message from the analysis is the dominance of negative issues focusing on cost, staffing and lack of knowledge. As Table 5 further illustrates, one of the main barriers to business engagement with DF initiatives is budgetary constraints particularly, but not exclusively, for small businesses and charities.

Tables 5 here

The issues raised in this section demonstrate that there are *perceived negative costs* and that there is a *lack of information and knowledge about what steps to take*. Again, the latter might be related to perceived costs in both money and staff time in engaging in training. A further point that emerges from this is the need for a lead on advice and training through a principal organisation.

4.3.3 Organisation for a dementia-friendly (DF) visitor economy

Leadership within the visitor economy emerged as a key issue where a lead organisation is needed to take actions forward in a consistent way, and to communicate, co-ordinate, and inspire on dementia initiatives. There was a strong theme throughout the interviews that, given interest and in some cases enthusiasm to participate but lack of knowledge of how to become DF, a top down approach would be the most useful to businesses. In addition, a funding or pump-priming role might be part of this remit. Some favoured a public sector lead (through local councils and a dedicated officer to devote time to the topic, or through the DMO), while others advocated professional bodies or groups within specific sub-sectors of the visitor economy which would have easy channels of communication open with existing businesses. In support, it was noted that where a local council had an initiative running it had inspired one business to get involved in training and develop its facilities. This, however, is not widespread practice on a national scale. In contrast, another view came from enlightened staff in organisations where they saw a need to convince their governing body to invest or allow staff to develop initiatives, emphasising an internal focus. Further, the idea of inspiring businesses was mentioned several times, for example to engage an inspirational leader or *"ambassadors that are leading that are big names that are and can say how easy, and how much effect its having…"*. What is also clear is that practical support is needed.

4.4.4 Support for DF business actions

Similar to the need for an organisational lead, businesses made it clear that practical support and advice is essential. Businesses identified several themes relating to how this support might be best delivered (see Table 6).

Table 6 here

Through developing the infrastructure required to build a DF, businesses can move towards a position of advocacy as part of their business operations.

4.5 Stage 4: Advocacy

Two perspectives relating to advocacy of dementia awareness and initiatives within the visitor economy emerged from the literature, incorporating a business/organisational perspective and a personal role. Some businesses and organisations view themselves as adopting an advocacy role, although these are mainly but not exclusively confined to the museums and galleries sector, particularly given the need of this mainly public-funded sector to demonstrate public good, a recurring theme in this paper (see Table 7). For some elements of the visitor economy, developing an environment that recognises the needs of people with dementia is essential, and this is viewed as more applicable in specific types of attraction. The power of museum experiences, for example, as

recognised within a developing strand of literature, and further confirmed in this study, indicates the positive impact garnered through a focus on reminiscence.

Table 7 here

While there is certainly an element of acknowledging that dementia awareness is, as noted in one interview, *"good for society and beyond*", more tangible aspects of business practice emerged as a much more dominant theme in this research, primarily focusing on how businesses can promote DF practice to benefit their bottom line which was a related theme highlighted in Table 8.

Table 8 here

As can be inferred from Table 8, businesses and organisations engaging in DF initiatives have a range of motives, some of which are financially driven (explored further in the next section) while others take a more developed civil society view, for example *"…I don't know if it would be for us profitable. It would be more a case of we want to be accessible for all"*. Nonetheless, cost perspectives are a substantial factor and few businesses promote dementia friendliness as a key market proposition. However, most acknowledge the opportunities for market widening, audience development and income boosting as illustrated in Table 9.

Table 9 here

As Table 9 suggests, the potential for PR gain is clearly recognised by businesses. In terms of business operation within the visitor economy, a positive issue acknowledged by some businesses is the opportunity to develop new audiences to assist with seasonality and/or times of lower demand outside peak tourist season, and periods of the week when demand is lower (e.g. weekday mornings). From this position, mechanisms for businesses to engage with dementia initiatives and be in a position to support customers with dementia need to be promoted via the simple steps that create a DF environment. Some recognise that this is achieved through promoting the ideas as noted by one participant that *"…it's not difficult when it comes to it…dementia friendliness by comparison [to wheelchair adaptations] is so easy"*. Businesses often have the basis of the necessary DF attributes (such as good customer-facing staff and good signage) but could build better advocacy platforms to promote DF features, for example, as one participant noted, through advertising: *"I think it's just about their advertising…It's how it's promoted, that it's very inclusive".* Furthermore, this participant noted that in relation to the wider business community, *"…it's in their benefit to advertise the fact and…dementia friendly badges, that's really going to be a bonus to [businesses]".* This is an important point given the enticement for businesses to participate in initiatives that allow them to earn certification and the use of a logo as an external symbol of their commitment as a DF establishment. Several schemes operate within a UK context, most notably Dementia Friends, Purple

Angels and other structures operating in specific locales, including DF communities operated through Dementia Action Alliances. In the survey, four businesses had joined a DFC or business scheme, 22 were not members and five did not know. Of those who were not or unsure whether members of a scheme, 22 would consider (11 would definitely consider), while five were unsure. While advocacy is a step in the right direction, the true essence of inclusion is still some way off. However, as noted by one participant, "*There's a lot of evidence there that suggests that making your business more accessible to people with all sorts of… problems and difficulties is just good for business".* Accessibility was a separate sub-theme raised by interviewees

4.5.1 Promotion of accessibility for people with dementia

While there is consensus and eagerness to develop services that are as accessible as possible to all visitors, a more fine-grained analysis indicates some of the deeper issues for businesses and organisations. First though, as noted by one interviewee, *"to be completely inclusive you're not just coming at it from a point of view of disability"*, an issue recognised in the dementia literature and in dementia care but less so in the context of this study, where the majority view is that dementia is very much part of accessible tourism practice. This indicates there is still some way to go in mainstreaming dementia as part of society. Given the focus on accessible tourism by many respondents, the key emerging issues cover a range of challenges for businesses. Justification for investments in making sites more accessible (beyond the basic standards needed to comply with legislation) is an issue for some given resource constraints. This is particularly an issue for nature-based and heritage organisations that oversee a large number of sites, some of which are in remote areas as opposed to sites nearer centres of population where it can be hard to make sites comfortable for all (e.g. paths and trails in outdoor environment. For example, developing low-key sites away from larger centres of population may not be resource effective *"…we do try and think which of our sites are the most valuable for this…most suitable in terms of geography…"*. In terms of accessibility, participants expressed an eagerness to get involved, from: *"we're quite keen to lead the market…we're hoping to try and get in there beforehand…"* and *"we're quite keen…"*, through to *"we're actually starting to look at [signage and set up for group visits] now…"*, with a range of practical steps being applied within premises, to the visitor journey and in promotion.

4.5.2 Steps taken

The practical steps taken within attractions are quite varied, with some examples are illustrated in Figure 4, which combines the findings from questionnaires and interviews. Knowing what can affect people with dementia, means that organisations need to find out and make changes, many of which can be simple or may create more of a challenge (e.g. removing the shine from marble surfaces) or have a wider resource implication (e.g. replacing carpets that create visual disturbance). In the

survey, seven of the 31 businesses had made some adaptations for customers with dementia. Three of these businesses felt that the adjustments had yielded new business, while others felt that these adaptations catered to the needs of existing visitors more effectively.

Figure 4 here

4.5.3 Ways of working with industry

As recognised in Stage 3, dementia awareness needs a strategic push, and the general consensus appears to be that DF initiatives are best promoted through a lead organisation, which could be a professional or membership organisation to work as an advocate for dementia awareness and improving experiences. In this regard, as one participant states, *"…communication and how you put it across to people is just as important"* as the issue itself in an attempt to engender understanding. Working in partnership with other organisations is perceived as a key part of progressing the DF agenda. A number of existing and developing collaborations were mentioned in interviews including those with and between government organisations, destination marketing organisations, local councils, Alzheimer's Scotland and organisations. Essential to this is good communication with businesses, as noted by one participant who stated that *"the actual selling of it is really quite crucial"*. There is a need to convince businesses with key messages, essentially *"why dementia and why not others?"* and to stimulate owners and managers to identify the strategic importance of dementia to their business. Part of this involves establishing and communicating an evidence base. From an organisational perspective *"businesses like stats, if they could get evidence as to… how [they could] attract more people with dementia along to their businesses they would probably like to see how much they are going to bring in because for a lot of businesses it's all about money"*. A second part of this incorporates observing peer practice and learning from market leaders who have embedded DF into business practice and services, as identified in one interview: *"look for market leaders to show how it is done"*. Case studies, communicating best practice across sub-sectors and evidence of what works well are needed to convince businesses to invest time and resources, with a commonly held view being: *"looking at it purely as a business decision, you look at the cost of whatever it is that you need to do and you look at the potential market that's out there and if you think that the potential market is going to be worth the cost then businesses are going for it"*.

Further issues in establishing advocacy for DF arising from the research included how to provide facilities bearing in mind that dementia is so diverse and symptoms change though time: in essence, one size does not fit all people with dementia, a feature reiterated by Alzheimer Scotland in relation to the creation of DFCs too (see http://www.alzscot.org/dementia_friendly_communities). One interviewee mentioned the difficulty of knowing how to talk to someone so it doesn't trigger negative responses and difficulties. Having a general awareness is perhaps different from having the

in-depth understanding of the range of responses that might be witnessed when someone with dementia reacts badly to a physical environment or social setting. An additional concern is not being able to evaluate the effect of training – what happens, what changes take place: where organisations work as advocates, what changes occur as a result?

4.6 Stage 5: Key Proposition

The survey revealed that some 90% of the businesses agreed with the statement 'I would like to make my business more DF'. However, few businesses were planning to make any adaptations – 27 said 'not sure' or 'no'. Only one business stated that they would be making changes within the next year. One of the obstacles appears to be lack of information. All the businesses surveyed agreed that they would like more information about how to make their business more DF. No business said that they were not interested in DF initiatives, and 87% agreed that developing DF initiatives is important for the tourism industry. The recognition that dementia 'is out there' and that businesses and organisations in the visitor economy can engage in activities to maintain and improve quality of life is recognised by many, with the spin off impact of being good for business is as one respondent commented if: *"we can help them enjoy coming to the centre then that…brings us more visitors and brings us more business…so there's a definite benefit"*.

Dementia friendliness is not a key proposition for many organisations but for those organisations for whom it is, there are some clear patterns. Most of these organisations are museums, which appear to spearhead the visitor attraction sector in terms of DF initiatives given their dual purpose as a visitor attraction and a community resource (see Genoe & Dupuis, 2014). As such there is a high degree of crossover between developing services, programmes and initiatives for local people and those that might also appeal to visitors to a destination. For museums, as one participant frames it, there is a commitment to go *"beyond what is the law because of the nature of our organisation"* and a sub-theme reported in Table 10 is the extent to which becoming DF was a key part of business delivery and part of 'doing the right thing' (Table 11).

Table 10 and 11 here

A strong theme emanating from those interviews where organisations had placed DF as a key aspect in service delivery was that of working towards the enhancement of visitor spaces and services with dementia inclusivity in mind through new signage, other adjustments to the physical environment and investments in staff training. With a national goal for destination accessibility rather than just a few geographically scattered businesses, there is some progress to be made in connecting organisations and businesses in a more concerted effort towards making the visitor economy inclusive to people with dementia, and a greater degree of normalisation.

4.7 Stage 6: Normalisation

The concept of normalisation focuses on the seamless integration of the needs of people with dementia without separation or making into a niche activity or market. As one interviewee commented, *"it's about mainstreaming it more so that more people are aware of it and it's not seen as something that you can out in a corner and just ignore"*. One interviewee who works in a museum setting typifies how this might work, where visitors *"…can just walk in and 'be'…we're trying to make our venues accessible so that you can just walk in and take out, do as much as you can with the objects we have on display"*. In this scenario, there is no expectation that people should have to identify themselves as people with dementia: *"I think that's having an independence, visit us without us ever knowing about it as such, and it would be ideal…"*.

Elements of normalised thinking are inherent in the views of several participants. For one participant dementia is considered a: *"…part of life and we probably need to adapt better to be able to deal with these things".* Another view of dementia is that it is *"…just the way our society has developed and we just have to find the best ways of dealing with it…It's just something we all have to recognise and get on with as it were"*. In recognition of those already engaged in DF initiatives, a further point was *"I think the people who are doing it and putting the research in and really developing programmes I don't think they see it as an issue. I think they see it as kind of something necessary"*. Such views indicate the move of some people towards a more caring and inclusive society as discussed by Thomas & Milligan (2015).

4.7.1 Moralising and de-stigmatisation

Many views relating to the moral obligation felt by some for becoming DF were expressed in interviews. One view on this is that these are activities that the sector *"should be doing as a matter of principle really"*. The need to connect with people with dementia to develop appropriate services and facilities is also recognised where business will *"…have to engage with people with dementia and the people who are looking after them and find out what they need"*. Moreover, there is a sense from this study that businesses do recognise their role, for example: *"we need to be adapting how services are provided"*. The cost implications for some organisations are real but to progress towards a state where dementia is normalised, as one interviewee commented about making adaptations and investments in services for people with dementia in the visitor economy, *"at the end of the day if [people with dementia are] engaged and enjoying it that's entirely enough reason to do it"*. New visitor spaces can incorporate the principles of good design for people with dementia, where facilities can be created with accessibility in the planning stages, an experience reflected by one interviewee where a new museum space had been created in partnership with a disability access panel so the space was suitable for all users: *"I was just trying to get it right in the first place"*. In

another museum, all staff had gone through dementia awareness training which was seen as a normal part of practice, involving special tours, and proficient staff as well as partnerships with care homes. One final view is that *"I would love to let them live life the way they still want to and just be out and about and live life as normal as possible"*.

Given the negative connotation of dementia, the need to reduce the stigma (see Milne, 2010; Swaffer, 2014) attached to the disease is a long-term process within society as highlighted by WHO (2012) and Figure 2. In the visitor economy, there are some early indicators of practice that can lead the way. These are inherent in approaches that avoid a patronising attitude to people with dementia, promote normalisation and resist:

- the idea of labelling places by providing "…*the right information then people can make their own judgement as to whether the site is suitable for them*".

- being condescending to and separating people with dementia from the mainstream. Good customer service, visitor orientation and clear information are important parts of the visitor journey for all, not just those with dementia and all public spaces can benefit from clear signage: "*If it works for people with dementia, it's likely to work for anybody*".

- the notion of stigmatising where "you don't have a set of things for people with dementia that's different for people that don't have dementia".

- the idea that people with dementia are different: "*these people still want to lead a normal life*".

What these approaches infer is that whilst normalisation might be an ideal, for some businesses and organisations it is a realistic proposition, albeit perhaps imperfect at present.

5.0 Study Limitations

There are a number of limitations to this study particularly in the survey, given the low response rate, which may have been completed by people with an interest or some knowledge of dementia and ignored by those (i.e. a larger number) of those who have not considered it. As such, this may be a self-selecting sample that does not necessarily reflect the wider business population. However, given there was a spread of responses across different response categories, the survey does at least give some indication of perceptions and attitudes towards dementia in the visitor attractions sector as a key component of the visitor economy. This may also be an issue in the qualitative stage of the study. Nevertheless, the interviews were undertaken with a range of people, some of who had personal experience, some who did not, and those in organisations with varying levels of dementia friendliness to reduce bias. The same interview schedule was used for each interview with variation

permitted to probe answers where required or to follow up on issues arising from questions. As such, the same basic structure underpinned each interview although length and depth of discussion varied. There is also evidence from the wider literature and experiences of disability and tourism that imply that some businesses may be camouflaging their responses, by saying the right thing but not changing their practice (see Ross, 1994; Ross, 2004) although from the interviews reported here, we did not get the impression that this was occurring in the case of people with dementia.

6.0 Implications

The research findings, whilst based on an exploratory research methodology, highlight implications regarding the extent to which businesses are aware of and engage with dementia, particularly around customer-facing issues. First, it is evident that the needs of people with dementia and their carers is a missed business opportunity because businesses do not have sufficient understanding of dementia. One may infer from the interview transcripts that the language used and degree of hesitancy in answering some questions indicated a degree of discomfort and tension in discussing such a sensitive issue, where respondents were unsure of the language to use and precise terminology. The poor response rate to the survey may demonstrate both the desire to ignore the issue and low level of awareness amongst businesses as reported in other similar studies. Even initiatives such as Dementia Week and a growing level of media awareness of dementia has not permeated business to a significant degree if these results reflect the situation across the visitor economy. This is supported by the second key implication – that many business owners and managers who responded to the survey and interviews would like more information on the subject. Yet this needs qualifying because many owners and managers are too busy to receive voluminous material and effective channels of communication are needed to convey key messages. In addition, there was a clear message that leadership by a trade body or Destination Marketing Organisation would be the most effective in promoting adoption of new practices on hidden conditions like dementia. Therefore, important initiatives such as the NCTA website materials could potentially be rolled out to lead organisations in the visitor economy.

Thirdly, despite dementia not being classified as a disability, many respondents to the interviews classified this condition and its inclusion in business activity as part of a widening accessibility agenda alongside other conditions and disabilities. The outcome is that dementia raises wider debates about social inclusion and what a civil society should do for members who perceive barriers to participation. Issues around disability and encouraging access among excluded social groups have dominated much of this debate on accessibility in the visitor economy. Yet new concepts around accessibility are now coming to the fore that are framed around hidden conditions without visible and physical cues such as autism and dementia. This new rhetoric and policy language is seeking to

advance the inclusion and accessibility debate as exemplified in 2016 in the lobbying of the Prime Minister's Dementia Challenge Working Group on Air Transport. With intervention from the Minister of State for Transport, a consultation was initiated by the UK Civil Aviation Authority on hidden conditions to ensure all airports are compliant with the 2010 Equality Act to meet the access needs of all travellers irrespective of any hidden condition. The lead from Gatwick with its implementation of a voluntary lanyard system for travellers with stated hidden conditions is a positive step forward. However, the airport and airline sector is a very small element of the visitor economy and this solution to raise business and service provider awareness of such issues in the confines of an airport and aircraft cannot be replicated across the visitor economy. Extensive training and coordination also accompanied this example of an innovation in the aviation sector.

Fourthly, these results pose numerous challenges to the model presented in Figure 1, since the findings suggest a modification of the model is needed to acknowledge the implications of not only the barriers to innovation but an overlaying set of factors that shape the precise responses of individual businesses. This research does not confirm that progress and transition towards a civil society where people with dementia and their carers will become normalised in the visitor economy in any specific timeframe. What is acknowledged is the need for pragmatism and recognition that much of the visitor economy comprises SMEs with limited training resources, staff retention issues, in some cases, low profit margins to devote major resources to hidden conditions. Perhaps a more appropriate interpretation of Figure 1 and our results is that this model may be viewed as appropriate to those businesses willing to embrace this agenda and pass through the stages to advance this issue. This also requires a more comprehensive approach, especially in tourism as one element of the visitor economy, whereby specific destinations decide to embrace this target market and create experiences in the visitor attraction sector and in the supporting infrastructure as advocated by Crampton et al. (2012) and illustrated in the case of York.

According to Crampton et al. (2012, p. 41), the notion of 'dementia tourism' development in the case of York would require a strategy to: market hotels, shops, restaurants and tourist attractions through customer or independently rated reviews; improve understanding of the needs of people with dementia within tour guiding and information services; allow websites to be searchable for DF providers; link with specialist tourism providers (e.g. Dementia Adventure) and Torbay Dementia Action Alliance in South West England with its pioneering to coordinating DF activity.

To date, no destination has sought to promote itself or position itself ready to become a DF tourist destination and Figure 2 illustrates that there is a great deal of work to do in the visitor economy to implement a coherent approach in specific localities that will ultimately need to pass the acid test of dementia-friendliness. This theme is further illustrated in Figure 5 which summarises the

implications of this study for destinations around four key challenges in seeking to make destinations more DF: is the place attractive to people with dementia and their group? Does the locality have the people trained and capable of responding to their needs? Does the destination have the necessary networks of people and businesses prepared to support the DF initiative and commitment to make a difference? Further, is this underpinned by the resources of both the public and private sector to ensure the visit is a seamless and enjoyable for people with dementia and carers so they return and communicate their experiences to others to grow the word of mouth recommendation?

Figure 5 here

While developing the DF destination may be a less desirable outcome than normalisation across an entire society, it offers a return on investment for destinations able to offer the complete range of supporting experiences across the visitor economy. Such an approach would allow destinations to work towards the normalised agenda where the condition is championed and accommodated in a supportive and seamless manner rather than an ad hoc treatment or with businesses paying lip service to the issue.

6.0 Conclusions

As Crampton et al. (2012, p. 17) emphasised, a diagnosis of dementia can result in withdrawal from leisure or recreational activities because people with dementia may feel unwelcome or simply not recognised in the visitor economy. While it is not the intention of this paper to argue that people with dementia should be targeted as a lucrative market, with appropriate levels of support the level of business engagement to increase dementia awareness and generate increased business from people within the local community and visitors alike could be elevated. In the visitor economy where emotional labour is a key element in making customer-facing experiences special, there is a clear need to understand how businesses should interact and communicate with people with dementia and carers and group members in a suitable manner.

A major incentive for businesses to become more DF is the increase in numbers of people with dementia over the next twenty years and their purchasing power within the visitor economy. As Crampton et al. (2012, p. 27) acknowledge, people with dementia do not often like to admit they have dementia, or to ask for help. This means they may need to be helped to find a way of telling people they have dementia and, because of it, they need extra time or to be given some specific support. To others, they may come across as defensive, withdrawn, or ‘odd’ and the response from others can be variable in consequence. Research confirms that it is not a simple process to know how to help their customers or colleagues who may or may not have dementia, or to always get

their approaches right. The visitor economy will need to equip itself with the skills and knowledge to make people with dementia feel comfortable, safe and welcome so as not to feel excluded from many activities that were previously a key element of their social life and leisure time (e.g. taking day trips and holidays) in the visitor economy.

Whilst this study is exploratory, it raises a major theme of significance to the global visitor economy in dealing with visitors, irrespective of whether they are day visitors, tourists or residents enjoying their leisure time. As the first assessment of one sector of the visitor economy, this study has illustrated the implications of how a civil society seeking to embrace people with dementia as a normalised experience is probably only just embarking on a long and potentially challenging journey in the UK and potentially in other countries. It is apparent that there is a wish to do more to extend a helping hand to people with dementia and their carers, but the steps towards DF are less understood. Awareness of simple innovations that are inexpensive, long lasting and able to address the needs of people with dementia was low among businesses in this research study.

The "d" word remains a sensitive issue and for busy people in business, engaging with this issue needs to be simple, cost effective and able to generate tangible business opportunities. Further research is needed to validate the experiences reported in this paper to create a better understanding of other sectors of the visitor economy as well as the impact of interventions and beacons of DF activity (e.g. Dementia Action Alliances) in moving the DF and DFC agenda forward in specific localities.

This study has only looked at one facet of the DF agenda in one country and in one sector of the visitor economy but the findings suggest that dementia is a major theme for the sector as a whole. Focusing on the attractions sector, which engages visitors from the local community as well as farther afield shows that progress is very much at an embryonic stage and is likely to gather momentum as the scale of dementia grows and reaffirms the initial findings of studies of ageing (e.g. Barclays, 2015) that depict this market segment as a still somewhat hidden element of the visitor economy. Further research will need to investigate how different organisations will lead the implementation of the DF agenda, including coordination across different agencies, perhaps drawing upon exemplars of localities that have better understood the wide ranging issues that need to be connected across the public and private sector. Such research, should as a key outcome, enable communities and their visitor populations to be better catered for within a transition towards a civil society where hidden conditions such as dementia are routinely accommodated.

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FOOTNOTES

[i] It embraces the hospitality and tourism sector (food and drink provision via cafes, restaurants and accommodation), travel agencies, transport providers, cultural activities like galleries, events and retailing. There is often a blurring of the terms visitor economy, tourism and leisure as residents may also use the facilities and services in their leisure time. The term broadly refers to the supporting infrastructure that caters

for the needs of visitors and residents especially in their leisure time and so is very wide ranging in what is included in such a categorisation.

[ii] A dementia friend is a campaign by the UK Alzheimer Society (https://www.dementiafriends.org.uk/) to challenge perceptions about dementia with an ambition of changing the way the nation thinks about and debates dementia. To become a dementia friend involves attending an online video course or face to face session run by the Alzheimer Society champions so participants leave understanding how small actions can make a big difference. Other schemes such as the Devon-based Purple Angels (http://www.purpleangel-global.com/) pursues similar objectives on raising awareness and stimulating action on dementia in local communities.

[iii] This recognition is currently under being reviewed to assess what being a DFC means within a community setting following the number of communities now signed up.

[iv] For the purposes of conceptual clarity, as highlighted by Connell, Page and Meyer (2015) identified the different markets which visitor attractions appeal to (residents as day trippers), other visitors undertaking a leisure trip and tourists on holiday. Within the context of this paper and for the focus of this journal, tourism can be conceived as part of the wider context of leisure rather than a narrow focus simply on holidaytaking as explained in more detail by Hall and Page (2014).