



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



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## HIGHLIGHTS

- Dementia is a growing global health issue.
- Tourism organisations and businesses need to be aware of how to adapt business practices to dementia.
- Dementia is a hidden condition making it a challenging issue for service businesses.
- The development of a dementia-friendly businesses in the visitor economy are discussed.

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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.

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## 1. 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, 1767 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, 2015), the application of civil society concepts across a range of social, cultural, religious, political and other divisions remains of global relevance (Birks, 2016).

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

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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<sup>1</sup> 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, and 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 [Goodall, Pottinger, Dixon & Russell, 2004](#); [Imrie, 1996](#); [Imrie & Hall, 2001](#); [Oliver, 1996](#); [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 a 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. they were 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 Organisation \(WHO\), 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, although 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 and 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 and 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’<sup>2</sup> to raise awareness and understanding of

<sup>1</sup> 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.

<sup>2</sup> 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.

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