A LITERATURE REVIEW BY TILLER RESEARCH ON BEHALF OF VITALISE

Literature Review

A review of the literature on respite care provision

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Introduction
This literature review focuses on the current provision of respite care / disabled Holidays in the UK. It particularly focuses on the views of the Government and disabled advocacy groups regarding the provision and funding of respite, and the effects of the recent government spending review upon these services. Literature was also studied relating to the views of respite care held by disabled people and their carers.

Methodology
General internet searches were conducted using Google and a government documents website[1]. Academic search engines were also searched for relevant journal articles, and these included the University of Birmingham's CrossSearch facility[2], DeepDyve[3], PubMed and www.google/scholar. Priority was given to literature published in the last 5 years.

Results
The results of the literature review are presented in the following sections:

1) EVIDENCE OF AN URGENT NEED FOR RESPITE CARE

High need; Low use
The literature demonstrates a high need for respite, but low usage of services has been found with places often remaining unused and people often failing to return following their initial experience of respite (Kelly and McSweeney, 2009). The MS Society (2009) found that 42% of people with MS, and 35% of carers, had not used any respite/ short break services in the past year. Usage was higher in those with higher care needs, yet still 20% of people with constant care needs had not used any respite services in the past year.

A survey of carers of people with COPD[4] revealed that over half received no help at all with their caring role. The majority of those surveyed felt that caring affected their own health, most often their mental health in terms of stress, worry and depression. Insomnia and broken sleep were frequent problems for these carers and over half provided some care during the night seven nights per week (Lung UK, 2007). An Italian study of the caregivers of Alzheimer's patients found that, as the disease progressed and the amount of time they spent caring increased, their free time decreased and levels of anxiety, stress and care-related burden increased. Towards the end stage of the disease, carers (mostly spousal) had on average only two hours a week to themselves, and

[1] www.official-documents.gov.uk
[2] Online elibrary service of The University of Birmingham. Searches restricted to the Humanities and Social Sciences, Medical, Life and Health Sciences journal databases.
[3] Pay-per-view academic search engine
[4] Lung disease

their independence was almost entirely lost. A review of the literature revealed that carers can feel physically and emotionally affected almost all of the time, especially in the later stages of disease (Mullan, Acheson and Coates, 2011).

Families reaching crisis point

Failure to access respite services can lead to the deterioration of caring relationships (Parkinson's Disease Society in Scotland, 2008). A UCL survey of family care-givers of elderly relatives with dementia found that 34% of carers had behaved abusively towards the cared-for elder in the last three months, most commonly displaying verbal abuse (Cooper, Selwood, Blanchard *et al*, 2009). A systematic review of the literature on elder abuse concluded that abuse was generally unintentional and was often in response to carer stress and difficulty in managing the challenging behaviours of care-recipients (Cooper, Selwood and Livingston, 2008). Risk was raised when care-givers were themselves in poor physical and/ or mental health (Beach, Schultz and Williamson, 2005).

Several organisations have commented that they are unsurprised at such reports of elder abuse in families where carers have reached crisis-point, and that the situation is worsened by lack of carer support, including lack of adequate respite care:

"Most carers do an excellent job in very difficult circumstances, but without help and support they are placed under enormous strain. Giving carers access to respite, psychological support and financial security could help end mistreatment."

Source: The Alzheimer's Society, 2009

"Caregiver stress is a significant risk factor for abuse and neglect. When caregivers are thrust into the demands of daily care for an elder without appropriate training and without information about how to balance the needs of the older person with their own needs, they frequently experience intense frustration and anger that can lead to a range of abusive behaviours..... Respite care - having someone else care for the elder, even for a few hours each week - is essential in reducing caregiver stress, a major contributing factor in elder abuse. Every caregiver needs time alone, free from the worry and responsibility of looking after someone else's needs. Respite care is especially important for caregivers of people suffering from Alzheimer's or other forms of dementia or of elders who are severely disabled."

Source: American Psychological Association, 2011

Vulnerability of Older Carers

There is a continuing rise in the number of older carers in the UK. Sufferers from conditions which generally onset in older age, such as Alzheimer's, Parkinson's Disease or COPD are often cared for by a spouse/ co-habitant partner of similar age who may themselves also be disabled. The caring role may be mutual, and one or both carers may find their health further deteriorating as a result of their caring role. The demands of caring can deplete a care-giver's stamina and increase their risk of exhaustion and clinical depression (Age UK, 2010; Beach, Schultz and Williamson, 2005). Provision of respite care for older carers, who are often unseen, is therefore urgently needed:

"Older and co-resident carers have extra needs: An older couple are also more likely to be in a mutual caring situation, where both support the care needs of the other. This situation is particularly likely where one spouse or partner has been a long-term carer for the other and has developed health problems of their own..... Co-resident carers often report that, because they are co-resident, social care staff make assumptions that they will be there to provide the majority of the care and are more likely to ignore the carers' needs.

Source: Parkinson's Disease Society in Scotland, 2008

2) BARRIERS TO RESPITE CARE

Cost as a barrier

The cost of respite is a barrier to accessing breaks for many carers/ service users (APG Parkinson's Disease, 2009). Carers are often on a low income, due to having to give up work to take on their caring duties, or due to their own disability/ age, so have low resources to spend on holidays (Vitalise, n.d.). A case study of disabled tourists found that financial hardship meant several participants had not been on holiday for over 3 years (Shaw, 2004). A focus group consultation with carers found that many had suffered financial hardship since taking on a caring role (Lung UK, 2007).

Financial hardship means carers and disabled people are unwilling to eat into their personal savings to pay for respite care (Parkinson's Society in Scotland, 2008). Disabled people with higher care needs are more likely to find cost a barrier to accessing specialist respite services (MS Society, 2009).

Financial hardship – older carers

Older carers often face particular financial hardship as they can no longer work and find that their Carers' Allowance ceases upon retirement. Age UK (2010) found that some older carers do not even consider themselves to be carers, considering care to be part of their spousal rose. Consequently, many carers do not realise that they are entitled to receive assessment and support from social services for their caring role. Those who do are often confused about the benefits system, lack accurate information and lack the time and energy to navigate the system and research their choices.

"Older carers can struggle financially.... Initially they may be too traumatised and stressed to understand information or take it all in. Because of this they often fail to take up offers of support made at the time and they may have to come back to ask for help later. It is important that Carer Support Workers appreciate that older people need more time to process information about services, entitlements and benefits available to them. Carers Support Centres identified that many older people can be intimidated by official looking documents and pride can prevent people from accessing benefits, particularly those which are means tested. Participants emphasised how tired they can become and that they need easy access to information and advice..."

Source: Age Concern Durham County, 2011, p37

Lack of assessment

Age UK (2010) found that 54% of older carers they reviewed had not received a Carer's Assessment and that many older carers were completely unaware that respite care or Carer Breaks, funded by social services, existed. This situation was also identified by the APA on Parkinson's Disease (2009). Camden Carers centre identified the need to make carers aware of their rights to support, and implemented a strategy to work with local GP and hospital services to identify family carers and work with them, particularly in terms of signposting sources of support and facilitating their access to respite (Camden Council, 2010).

One problem with social services assessment is that respite is only offered in cases where Social Workers assess high levels of care need. Age Concern Durham County (2011) found that many carers, particularly co-habitant spouses, failed to meet this eligibility criteria, despite the significant effects caring had on their lives. Another report found, in a survey of over 3000 carers, that just over one in ten were receiving support from their local authority in spite of the fact that nearly two-thirds of carers were caring for 50 hours a week or more, with just a fifth caring for less than 20 hours per week (APA Parkinson's Disease, 2009).

Concern over the quality of respite services / care

A survey of stroke patients and their carers commissioned by the Department of Health (2010) found less than a third of respondents felt that some key support services, such as respite care, were of good quality. The Parkinson's Society in Scotland (2008) found that many carers' lacked confidence in the quality of respite care provided and that a poor respite experience often deterred people with Parkinson's and their families taking up respite opportunities in the future.

> *"It's not really a break if they're worse off because of poor respite"*
> *Source: The Parkinson's Disease Society in Scotland, 2008*
>
> *"I'm very concerned about standards and who is going to monitor it. It's a case of being frightened of the unknown."*
> *Source: BBC Radio 4, February 2011*

As government provision of respite centres falls, disabled people and their families increasingly have to turn to private sector services for respite care. However many people are afraid of the 'unknown' private sector, and worry about how standards are monitored and maintained (BBC Radio 4, 2011).

Box 1: Common reasons for carers' dissatisfaction with respite care:

- Failure to provide medication on time
- Lack of understanding of Parkinson's Disease, its symptoms and treatment (particularly the importance of timely medication)
- Failure to facilitate self-management
- Failure to provide adequate food and drink
- Absence of stimulating activities / entertainment

Source: Adapted from Parkinson's Society Scotland (2008)

A project to re-design a residential respite service in Eire reported that the a change in the organisation's attitude towards respite was needed, focussing away from the medical model to a view of respite as based on customer needs:

> *"[O]lder people often did not want to spend time in [a hospital] environment, sharing it with very frail patients. The experience proved rather depressing for a number, who either refused to attend in the first place or were unlikely to return.... Carers want respite that is relevant to their needs and those of the person they support, and that is of high quality, providing an interesting and stimulating experience for the older person... From the older person's perspective, they all need to see the break as being of some benefit to themselves as well as their carer"*
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> *Kelly and McSweeney, 2009*

Personalisation and Direct Payments

Government strategy is pursuing the personalisation agenda, increasingly moving towards the allocation of personal budgets to those who are disabled and their carers. These budgets may be spent on those services the budget holder feels will best serve their needs and improve their quality of life. These services may be either government run or private-sector services.

> *"Government is working across all departments to ensure that potential barriers to inclusion are identified at as early a stage as possible and, wherever possible, removed. Personalisation has a key role to play in this, together with choice and control. So the Government has made a commitment to extend the greater roll-out of personal budgets to give people and their carers more control and purchasing power, and to use direct payments to carers and better community-based provision to improve access to respite care."*
>
> *Source: Department for Work and Pensions, April 2011*

In November 2010 the Department of Health Announced that £400 million would be set aside for the funding of breaks for carers, and that everyone eligible would get a personal budget by 2013.

Personal budgets are often paid out by means of direct payments through which the allocation and procurement of services needed is managed by the individual. Some disabled people and their carers have welcomed these, yet some find the scheme, and the task of managing their finances, researching and buying services, confusing and burdensome, especially on top of their additional caring burdens [see Box 2 - below]. UNISON are concerned that some individuals who are unable to manage their personal care budgets in this way are being pushed into doing so by councils who want to save on administration costs (UNISON 2011).

Personal budgets are designed to give wider choice to service users. However, UNISON has expressed concern that some councils are restricting the use of personal budgets so that they cannot be used to fund leisure activities like holidays and computer equipment (UNISON 2011). Personalised budgets and carer support were identified as a strength in less than half of the councils assessed by the Care Quality Commission (2011).

Box 2 - Problems identified with Direct Payments from literature:

- Many carers are unknown to social services, and so never receive a carer's assessment.
- Many carers fail to meet their local authority's eligibility criteria for support
- Many carers do not understand that they are entitled to financial support and/ or respite at all
- Many carers do not realise that payments made to themselves/ their cared-for person can be spent on respite care / short breaks
- Many carers are too exhausted to navigate the benefits system and research their options
- Carers often have no access to the internet / other sources of information
- Some groups of carers have literacy problems, so have little / no information about support and services available to them

Eligibility Criteria for direct payments

Carers require a Carers' Assessment by social services in order to assess their eligibility to receive Direct Payments. Carers only receive payments if they meet the eligibility criteria set by their local authority. As seen above, many are unaware of the need for assessment, or fail to meet eligibility criteria. A report on Primary Care Trusts and the delivery of the National Carers' Strategy has found that many vulnerable and elderly carers are excluded from social care criteria (Princess Royal Trust / CrossRoads 2010). Scope (2009) have also raised concerns that vulnerable disabled people slip through the net of eligibility criteria.

Yet the debilitating effects of many illnesses, and the pressures on carers, often spouses, partners or family members, can be great. An American study found that respite holidays were beneficial to the spouses and children of adult cancer patients and helped them to cope with the practical and psychological impact of the disease (Schankweiler and Gambino, 2010). A report by MacMillian describes how cancer patients and their carers sometimes need short or longer-term respite breaks as lengthy treatment and illness often restrict ability to carry out everyday self-care tasks (e.g. stair climbing/ walking, lifting, cognitive impairments). However, MacMillian report that the needs of cancer patients and their carers for respite and carer breaks are often overlooked. This is because NHS staff often focus exclusively on the medical care needs of cancer patients, overlooking their social care needs and the support required by their relatives. When assessment is given, cancer patients often fall outside of the eligibility criteria. [MacMillan Cancer Support, 2009]

Some concern has been raised by various groups that individual local authorities are raising their eligibility criteria for social care funding as a means of reducing the number of claimants and saving council funds [Scope, 2009]. Birmingham City Council were judged unlawful and in breach of the Disability Discrimination act by a High Court ruling. A test case had been brought against Birmingham's Conservative-LibDem council by a group of disabled people, who charged the council with having raised the eligibility criteria to fund only those people assessed as having 'critical' levels of need, leaving people with 'substantial needs', such as themselves, without adequate social care support (Guardian, 2011).

Scope are also concerned that the ability of local councils to set their own eligibility criteria makes the system increasingly confusing for claimants, who do not know whether they are eligible for support or not, and make it possible for councils to withdraw or bar funding from claimants who need it in order serve the council's own budget management needs. Scope are currently campaigning for a national system of eligibility and entitlement, removing the discretionary powers

of local government and separating funding and commissioning roles [Scope, 2009]. An inquiry by the APA on Parkinson's Disease (2009) heard the case of Denise Maule, a wife giving round-the-clock care to her husband, who did not manage to access respite care until she reached 'breaking point', only to be informed that she was no longer eligible by social services a short time later, though her circumstances remained unchanged

Alternative funding sources

NHS funding

Local authorities emerged as the greatest provider of funding for respite. The MS Society Respite Review (2009) found that 47% of respondents were funded by their local authority and only 7% by the NHS. The Princess Royal Trust / Cross Roads care have expressed concern that only 23% of the £50 million given to PCTs in 2009/10 to increase their services for carers was actually used for this purpose. They also report that of the £100 million given to PCTs by the Government 2010/11, PCTs plan to spend only 26% of this on carer services. They also report that 25% of PCTs plan to reduce spending on carer services. A report by the Care Quality Commission (2011) remarks that the money held by PCTs for carer support has not been ring fenced, and that it has not always been apparent how this funding has been used.

Charitable supporters / grant-funded organisations

Although many charitable organisations do fund the respite care of individuals, the numbers funded are fairly low: 6% according to a survey by the MS society. Only six organisations offering this support to adults with disabilties were identified in the course of this review (Appendix A). The Care Quality Commission (2011) report that reduced social care provision has not been offset by help from grant-funded organisations, and estimate that the number of people benefitting from such services has fallen.

Some charities provide respite services, and some pay for the purchase of respite care, but many are seeing the grants they get from local government cut, and this is leading to a cut in the services that charities can provide as their own funds fall. Health journalist Sara Burke writes about the decrease in Irish charities' provision of respite care following government cuts:

> *"Some services have been cut and others are planned for cuts in Limerick, Dublin, Galway, Mayo and Sligo. This is happening because quite simply budgets are being cut. If we take the Daughters of Charity in Dublin, last year their budget was cut by €3m, this year they have received a €4 million cut, on top of staff reductions and Value for Money efficiencies.... In disability care, as in much of social care, the majority of costs is staff. Care takes people. The Daughters of Charity in Dublin feel they have no choice but to reduce services so as to live within budget with fewer staff..." (Burke, 2010)*

Transfer of services to private-sector providers

The Care Quality Commission (2010) reported that the largest increase in spending in adult social care during 2009/10 was in the provision of direct payments to carers, which 33,883 people received for the first time. The same report showed a sharp reduction in the amount of people receiving community care services, including respite care, despite the numbers of people identified

with a disability or chronic health condition increasing. This may point to an increasing role for the private sector in providing community care services, including respite, which those receiving direct payments will have the opportunity to purchase. Oldham Council have proposed savings of £680,000 by changing the use of two in-house residential homes for older people into long-term care services, transferring short stay and respite provision to external providers (Oldham Council, n.d.).

Little focus on non-emergency adult respite services

Many local government strategies are focussed on home-based and emergency respite, with no mention of non-emergency short-term residential care / short breaks (Camden Council, 2010). The Alzheimer's Society have expressed their view that short breaks should be funded too, not just crisis point intervention (The Alzheimer's Society, 2008). The Princess Royal Trust / Crossroads care (2010) report that there is a PCT / NHS focus on respite for the carers of disabled children.

Lack of provision

Long waiting lists for respite places, and for carers' assessments, were found to be a significant barrier to accessing respite (Parkinson's Society Scotland, 2008).

There is some evidence that provision of respite care and funding for respite is decreasing following current spending cuts. A survey from by the Care and Support Alliance (2011) found that unmet need is increasing and 57% of carers reported that recent changes have had a negative impact on their ability to have a break from caring, such as respite.

There is also evidence that some carers of those with long-term conditions wait until the later stages of the illness, often for many years, before seeking support in case early provision leads to a rationing of help in later years. These carers are aware that support is limited, and do not want to 'use it all up' before they really need it (Parkinson's Society Scotland, 2008)

Some groups have expressed concern that difficulty in the recruitment of specialist nurses for neurological disease leads to a lack of specialist respite provision for those with Parkinson's disease (APA Parkinson's Disease, 2009)

Travel as a barrier

Many low-income families find additional costs, such as travel to and from centres, a barrier to accessing residential respite care (MS Society, 2009). The Parkinson's Society in Scotland (2008) found this was a particular concern for those living in rural and remote areas, where public transport was unavailable or unsuitable, and the distances to respite centres were great. The unaccommodating and uncomfortable nature of some public transport services was also found to be a barrier to taking holidays by disabled tourists (Shaw, 2004). Many disabled people cannot drive and struggle to fund the costs of driving lessons, car adaptations, car ownership/ rental or private taxis. Disabled advocacy groups campaign to ensure that disabled people receive funding to support their need to drive / use public or private transport (The Parkinson's Society in Scotland, 2008).

MS Society research found that lack of local availability was the most common reason members had not used one of their three MS-specialist residential respite centres. The recent decision taken by the MS Society to transfer the running of their residential respite centres to the private-

sector was partly undertaken with respect to an increased need to cater for members who did not live near to the MS centres, and were therefore unable to access respite due to the cost and/ or physical difficulties posed by excessive travel:

> *"[F]amilies affected by MS who don't live near our care centres may get very little or no support from the MS Society to access short breaks and respite. We have a responsibility to support all people affected by MS, wherever they live."*
>
> Source: The Multiple Sclerosis Society, 2009

Lack of signposting

Evidence suggests that local authority staff often fail to signpost sources of support for other family members / carers when directing disabled people to available services (Care Quality Commission, 2011). Some evidence was found that disabled people and carers expected social services to approach them pro-actively with the information they required, rather than that they would have to approach services themselves:

> *"We specifically asked people what kind of support they had found useful when caring. In response, there was a clear message that well-signposted access to reliable information and advice was vital, particularly when people first become carers. People also welcomed opportunities for regular breaks – in particular respite care."*
>
> *Source: Department for Work & Pensions, 2010*
>
> *"One of the key themes that emerged from submissions to the Inquiry from people with Parkinson's disease and carers was that they did not know how to access services, particularly social services support. Many people did not know about their right to an assessment of need for care services, and many also wrongly expected that social services would approach them proactively. There is a sense that many people feel that have to 'fight' for information about, and how to access, services, and they are not being directed to other services by health and social care professionals."*
>
> *Source: APA on Parkinson's Disease, 2009*

Some local authorities and community groups are resolving to increase the signposting of services. Camden Carers' centre provided GP practices with carers' information packs which signposted services. They also run a variety of carers' information services, including some tailored to the local Bangladeshi community (Camden Council, 2010).

Older carers were often found to have problems with literacy and/ or lack of internet access, which can prevent them being aware of respite services available and the sources of funding open to them (Age Concern County Durham, 2011).

3) THE BENEFITS AND PROBLEMS OF RESPITE CARE

Benefits to carers

Many disabled people are well aware of their carer's need for a break and use respite to provide this service (Mullan, Acheson and Coates, 2011; Shaw, 2004). Lung UK (2007) found that many carers used respite to relieve their stress. Carers also report using respite periods to rest, take a holiday themselves, to catch up on housework, see friends and to spend time with other family members (Mullan, Acheson and Coates, 2011)

Age UK (2010) found that respite care was protective to the health of older carers, allowed them to maintain their own social life and interests and allowed them to continue caring for longer.

A study by Lee, Morgan and Lindsay (2007) found that the carers of people with dementia often suffered from insomnia and disturbed sleep, and that these sleep problems lessened during periods of institutional respite care.

> *"I wish it wasn't required, but I have three young children and they must be put first, even for part of the year."*
>
> *"I feel terrible that I am enjoying a holiday away with friends and my wife is in respite. But I realize I need a break because I feel stressed out at times."*
>
> *"Respite care means I can come and go as I please, my time is completely my own to relax, and I can go away for a few days."*
>
> *Source:* Mullan, Acheson and Coates, 2011

Benefits for disabled people

In one survey of people with MS, 47% went on respite because it provided increased opportunities for social interaction with others (Mullan, Acheson and Coates, 2011).

The opportunity to go on outings and experience new things was also found to be important and something which many disabled people, especially those with high needs, struggled to do at home (Mullan, Acheson and Coates, 2011; Shaw 2004).

A break in the normal everyday routine and to have a holiday was another benefit disabled people appreciated, along with a chance to rest. 64% of people with MS surveyed specifically enjoyed the chance to get away from home (Mullan, Acheson and Coates, 2011; Shaw 2004).

Respite offered a service for disabled people when their own carers where on sick leave or on holiday (Mullan, Acheson and Coates, 2011)

An Australian study of older dementia patients who entered a period of residential respite found that residential respite was associated with a temporary lessening in the frequency of reported disruptive behaviours (Neville, 2007).

Problems caused by respite care for disabled people and their carers

As has been discussed above, there is some evidence that both disabled people and carers worry about the quality of respite care and the ability of care staff to appropriately serve the needs of disabled people. Age UK (2010) found that carers of those with dementia were particularly worried about how the cared-for person would respond to strangers, and gave evidence of incidents where upset had been caused.

> *"I was offered residential respite care and sitting services for my wife but I did not want these as I was worried that she might become anxious and distressed or that staff wouldn't have the skills to manage."*
>
> *Source: Age UK, 2010*

An Irish study found that worry about the quality of the respite experience was a barrier to families of older disabled people taking up respite places (Kelly and McSweeney 2009). The study reported an initiative by a residential care hospital in Western Ireland where staff made efforts to create an environment that more closely reflected the older person's own home environment. This was done by a series of small changes, and began with increasing the choice of food on offer and the times of meals. The authors hoped that by attempting to shape the environment more towards the preferences of the customer's home life than the routines of hospital/ care staff, the respite centre would become more homely and welcoming to residents.

A literature review found no reliable evidence that residential respite care adversely affects frail older people (Mason, Weatherly and Spilsbury et al, 2007), though the authors did feel that good quality studies in this area were lacking. A study by Lee, Morgan and Lindsay (2007) found that residential respite lessened the sleep problems of the carers of those with dementia, but worsened the already disturbed sleep patterns of dementia patients.

A study of the feelings of 96 MS sufferers about residential respite care found that, despite most enjoying respite care, 6% were angry about requiring respite. The same study found that 57% of carers felt guilty about needing to use respite care (Mullan, Acheson and Coates, 2011). Negative emotions were also found in a study of female carers where carers often experienced conflicting emotions of relief alongside feelings of guilt and emptiness (Salin and Astedt-Kurki, 2007). It is important that the emotional barriers of worry, guilt and anger experienced by respite users, as well as practical issues, are acknowledged by social care services and respite providers. Despite the concerns of many carers, many reports do suggest that disabled people generally enjoy their experiences and the opportunity to spend time in a different environment (Mullan, Acheson and Coates, 2011, Shaw 2004).

4) PREFERENCES OF DISABLED PEOPLE AND CARERS FOR RESPITE CARE

Individualised services and personal control

Personalisation emerges as an important theme in the views of respite given by disabled people and their carers. In general, carers and disabled people want personalised care and personal choice over the respite they receive:

> *"Through the review, people across the UK have told us that 'one size doesn't fit all', and that they want more choice and control over their respite care and short breaks, and a wider choice of options to choose from." (MS Society, 2009)*

The MS Society found that their members had a strong preference for activities being tailored to MS / MS specialist services and this increased with their need for care (2009). The survey also showed that people with MS had a strong preference for social activities, during both short and longer-term breaks, and this preference was also higher for those with greater care needs (2009). Mullan, Acheson and Coates (2011) also found that MS sufferers and their carers would welcome increased activities and outings in respite.

Carers UK (2011) stress the importance that disabled people and their carers should have access to respite in a wide variety of forms, including from private providers, so as best to meet their individuals needs:

> *"Respite / short break care can be facilitated, not merely by a sitting service under the 1970 Act or a residential placement under the 1948 Act, but by other diverse mechanisms. For example, the disabled person or their carer might be provided with a direct payment to enable them to arrange the break themselves)[;] or they might be provided with a joint holiday...Break services can be provided by the statutory or independent sectors. It will therefore, be maladministration if an authority fails to explore the potential for the independent sector to meet a need for respite care – particularly where that need is not being met by the statutory sector." (Clements, L. / Carers UK, 2011)*

Despite the aims of many organisations to provide person-centred respite care, research has found that organisational cultures often contain a variety of barriers which make it difficult for them to offer person-centred care for dementia sufferers (Kirkley, Bamford and Poole, et al 2011). Qualitative analysis of a series of interviews and focus groups with frontline and management level staff revealed five themes in organisational culture perceived to affect the provision of patient-centred care. These were:

- understandings of what person-centred care means,
- attitudes to service development,
- service priorities,
- valuing staff
- solution-focussed approaches.

(Source: Kirkley, Bamford and Poole, et al 2011)

Kelly and McSweeney (2009) stress the importance of movement away from the medical model to a person-centred focus on catering for the needs of respite receivers:

"[A]rguably what is needed is a fundamental shift in the way we think about care of the older adult, in order to give people more of what they want and require...a move away from an over-reliance on the medical model, where care is dominated by the perspectives of doctors and nurses, towards a more consumer-directed approach....Environments that operate under this paradigm try to honour residents' desires and allow flexibility in care delivery such as sleeping and eating schedules, preferences in bathing, and choices of activity

Source: Kelly and McSweeney, 2009

Confidence in familiar services

Confidence in respite accommodation appeared to be linked to previous experience, as those who had previously used a respite centre were most likely to choose this as their first choice (MS Society, 2009). Carers UK also recommend visiting the location respite is planned for beforehand, and notifying staff of care requirements, emergency plans and contact details in advance to raise confidence in services and reduce chance of problems (Carers UK, 2011)

Holidays, not respite

Provision of respite services must balance both the needs of disabled people and their carers (Law Commission, 2011). Yet evidence suggests the two groups often have different preferences for respite care. Carers often rated respite care services as more beneficial than people with MS did (MS Society, 2009). People with MS (most of whom had not used an MS centre) were most likely to prefer a holiday break with care as their first choice of respite service, followed by a holiday break without care, than breaks in residential or nursing homes. Conversely, carers preferred the provision of residential nursing home care to holidays (MS Society, 2009).

People with MS rated the provision of social activities more important than carers did. Some, but not all, of the people with MS surveyed wanted their partner / carer to join them on their holiday break (MS Society 2009).

"The results may indicate that there is a much larger unmet demand for residential respite care services at holiday venues than in residential or nursing homes....it is clear that many people affected by MS want respite care services in holiday settings, with access to care provision. Furthermore the value of specialist support to people with MS and access to a range of social activities should not be underestimated."

Source: MS Society, 2009

The research suggests that, like people with disabilities, many carers crave a 'proper' holiday. Despite some evidence that carers have a preference for home-based respite care (MS Society, 2009), a carers' survey found that many carers wanted more than a short break, and seven out of ten carers felt that a break from caring for a few days was 'important' or 'very important' (APA on Parkinson's Disease, 2009). A series of carer focus groups by Lung UK found that 19% of their participants wanted longer respite or a complete holiday. 23% of the carers surveyed had not been on holiday in over five years.

5) CONCLUSIONS

The author found there to be a dearth of literature on the views of people with disabilities receiving respite care and going on holiday, as was also found by the authors of a recent paper on the subject (Mullan, Acheson and Coates, 2011). Somewhat more literature was available on carers' views of respite and barriers to the access of breaks by carers. A good deal of research has been done into the risks of the carer-burden, and respite has been found to offer significant alleviation of carer burden and burnout. The literature on the risks of elder abuse when carers reach breaking point is also an interesting illustration of the importance of respite breaks.

Cost emerged as a major barrier to accessing respite care. Clearly changes in Government funding policy, and local authorities' recent re-evaluation of budgets and funding eligibility criteria, mean that the situation is constantly changing and will continue to do so in the near future. Formal evaluation of the effects of government policy is scarce, possibly because changes have been too recently implemented for full evaluation to have been run. However, much anecdotal evidence, in the media and through the voice of advocacy groups, suggest that access to funding for respite will become harder to access, at least in the short term. Increasingly, the private sector will have a role to play in running services which were formerly provided by local authorities, and private care provision seems likely to be a growing market in the future.

Personalisation seems to be a trend both in Government policy and in wider policies of service provision as organisations attempt to tailor their services more closely to users' needs. Certainly, people with disabilities appear to want respite care that offers them choice, activity and good quality personalised care, rather than a rigid, 'one-size-fits all' experience. Disabled people face far greater restrictions than others when it comes to holidays, facing issues of finding accessible travel, suitable accommodation, appropriate levels of care, and having a generally lower incomes at their disposal. Despite this, many people with disabilities do want to enjoy regular holidays, and particularly to enjoy new experiences, social activity and travel to new places. Services that provide them with this opportunity will have great appeal.

6) VITALISE: Implications of the literature for future development

- The review shows that the carers benefit from respite, often even more so than the disabled people they care for. Yet, lack of signposting means that many carers are unaware of the services available to them, of their legally enshrined rights to a break and of the benefits of respite to their health and the well-being of their family. Vitalise must be pro-active in reaching carers and communicating not only their services, but the general importance of respite to carers.

- Carers, and especially older carers, can be hard to reach. The review shows many have no access to the internet, and may rarely go out. Social services and health professionals often neglect carers' needs when working with disabled people, and many carers have no contact at all with social services. Older carers in particular may have problems with literacy, and language barriers may be a problem for carers in ethnic communities. Vitalise may be able to communicate with carers through contact with Carers Groups and even GP services and it may be worthwhile to produce information and forge liaisons with these organisations. Non-print advertising, such as through radio or through giving talks to local carers' groups may also be a way to communicate with those with low literacy / language problems.

- Funding is a major barrier to accessing respite. Many carers are not eligible for social care funding, and many others are put off by the formal social care assessment process or the prospect of managing direct payments. Others in receipt of personal budgets are unaware of the services available, and what they are permitted to purchase. Vitalise could work with social services to signpost their services to service users, as well as increase their visibility on the internet and in the national / local media.

- Transport costs are a barrier to accessing respite centres. Vitalise might forge links with local accessible transport services / public transport / accessible car hire services to negotiate a discount for their customers. Advertising should also make clear the various locations of centres.

- The quality of respite offered concerned many disabled people and carers. Vitalise should seek to reassure enquirers and service users of how they maintain quality, the training of their staff and how they meet service users' needs.

- Personalisation of services was desired by many disabled people and carers, and this is the current direction of government agendas. Vitalise should review the extent to which they are able to personalise their service, and how opportunities for personalisation may be increased.

- The provision of good quality meals was shown to be important to carers and service users. Vitalise should review their catering provision, particularly with regard to catering, as far as possible, to personal needs/ tastes/ preferences for mealtimes, and providing a quality food service.

- The provision of stimulating and entertaining activities and new experiences were important to both carers and disabled people. Outings and social activities were especially desired by those with high care needs, and motivated disabled people to attend respite. Vitalise should review and develop the entertainment, activities and outings it can provide. Marketing of this provision may also increase bookings among disabled people desiring increased social activity / outings.

- There is evidence that the NHS is neither funding nor promoting respite to any great extent. Vitalise should communicate with NHS services, promoting both its services and the benefits of respite to carers and disabled people.

- Charitable funding of breaks is an option for a small sector of the market. Vitalise should research those charities which offer funding for short breaks and communicate this to enquirers / guests.

- The review demonstrated that many disabled people desire more holidays, rather than traditional residential respite care. Creating a flexible, comfortable holiday atmosphere, and providing the type of experience other people enjoy on holiday, is attractive to disabled people. Importantly, many disabled people also want 'peace and quiet' on their holiday. Vitalise might explore how different types of holiday experience can be offered, perhaps during different weeks or at different sites, to appeal to their broad range of guests.

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Appendix A – Six charitable organisations offering funding for respite care

Organisation	Fund	Amounts	Criteria
Independence at Home	Grants	Up to £750	Help for people managing long-term illness and disability at home. Grants made towards a wide range of goods and services which provide essential and pragmatic support which would be otherwise be unattainable.
The Ogilvie Charities	The Margaret Champney Rest and Holiday Fund	Typical award £200-£300	Funding holidays for carers and their families
Mother's Union	Away From it All Holiday Scheme	Unknown	The scheme is open to anyone under extreme stress. Applicants do not have to be a member of a church or any organisation. It is also possible for people to apply personally or on the behalf of someone else. Each diocese has a team of Mothers' Union members who organise the scheme. They will normally help with part of the cost of a holiday or with travel expenses. In some cases they are able to pay the whole cost.
Parkinson's UK	Mali Jenkins Fund	Up to £1000	The aim of the fund is to give financial assistance towards respite breaks that will improve quality of life.
Multiple Sclerosis Society	Short Breaks and Activities Fund	Unknown	
Cystic Fibrosis Trust	CF Holiday Fund	Unknown	Small grants available for CF sufferers aged 25 or under. Also advise on travel insurance for people with CF.

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