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Planning, commissioning, and delivering bespoke short breaks for carers and their partner living with dementia: challenges and opportunities

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Author contribution: MC collected, analysed, and interpreted the data and drafted the manuscript. DS provided critical revisions to all sections of the manuscript and supported the interpretation of results. SW refined the design of the explanatory model and structure of the results and CHJ provided constructive comments and suggestions to help hone the introduction, results, and discussion. All authors read and approved the final manuscript.

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Abstract

The importance of supporting unpaid carers for people living with dementia (PLWD) is recognised in adult social care policy both nationally and internationally. In the UK, social care legislation emphasises care and support should help people achieve the outcomes that matter to them in their life; this includes the opportunity to take a break from caring routines and responsibilities. Accordingly, there is growing policy and practice interest in short breaks provision to address the diversity of carer break needs and preferences and deliver meaningful outcomes for carers and those they support. This paper reports findings from qualitative staff interviews that offered strategic and operational insights into short breaks provision. It presents a dynamic model of the short break landscape in a region of Wales, describing factors shaping local and regional decision-making. The model identifies key challenges (barriers) and opportunities (enablers) that shape the planning, commissioning, and delivery of bespoke short breaks for spousal carers and their partner living with dementia. Through highlighting the interplay between complex context-specific processes and contingences, the model informs initial theory development in short breaks provision.

Key words: carers, dementia, qualitative research, short breaks provision, respite, UK health and social care policy implementation,

What is known about this topic?

- Supporting positive, sustainable caring relationships, through the provision of breaks from caring is a priority for social care policy in the four UK regions and other economically developed countries across the world.

- There are considerable challenges to planning, commissioning, and delivering short breaks that support the realisation of personal wellbeing outcomes for carers and for people living with dementia.

This paper:

- Presents an explanatory model of the short break landscape, depicting key processes, contexts and contingencies involved in shaping breaks provision.
- Contributes to the emerging evidence base on the characteristics of bespoke, meaningful breaks provision to support carers and people living with dementia to achieve personal wellbeing outcomes.
- Identifies key challenges and opportunities to inform planning and decision-making about short breaks provision.

Introduction

An estimated 50 million people are living with dementia worldwide (World Health Organization [WHO], 2020). The greatest risk factor for developing dementia is age, and in line with global population ageing characterised by the rising proportion of people aged 65 years and over (United Nations, 2020), this figure is projected to reach 82 million by 2030 (WHO, 2020). Dementia has significant social and economic implications, with an associated global cost estimated at one trillion US dollars (Pickett & Brayne, 2019). In the absence of a cure, societies rely heavily on the contribution and commitment of family or friends (i.e., informal unpaid carers) to support individuals with dementia to live at home as part of families and communities. The emotional (Braun et al., 2019; Meyer, Cullough & Berggren, 2016) and physical (Fonareva & Oken, 2014; Gilhooly et al., 2016) impact of caring is well

documented and transverses cultures and ethnicities (Alzheimer's Disease International, 2019). Supporting carers is a focus of international dementia policy (Pot & Petrea, 2013; WHO, 2017).

Breaks from caring responsibilities are recognised internationally as essential to support carer's health and enhance their resilience to care (de la Cuesta-Benjumea, 2011; Roberts & Struckmeyer, 2018). Various terms are used in the literature to describe breaks provision, including respite care, short breaks, and restorative care. Traditionally, a break for carers involves the person with care and support needs receiving 'respite care' at specified times through services such as day care, residential respite care or in-home respite care (Arksey et al., 2004; Rochira, 2018). While the benefit of these traditional service models to alleviate the 'burden' of caring, characterised by improvements on a range of carer health outcomes is established (Tretteteig, Vatne & Rokstad, 2016; Vandepitte, Putman, Van Den Noortgate, Verhaeghe & Annemans, 2019), these services are underutilised and acceptability by carers and the individuals they support is low (O'Shea, Timmons, O'Shea, Fox & Irving, 2017; Phillipson, Magee & Jones, 2013). The limited capacity of traditional service models to support personalised care and meaningful occupation for the PLWD (Morrisby et al., 2018; Leocadie, Roy & Rothan-Tondeur, 2018), alongside their lack of flexibility (Macleod, Tatangelo, McCabe & You, 2017; O'Shea, Timmons, O'Shea & Irving, 2019), underlines their limitations in providing a timely and meaningful break (Tang, Ryburn, Doyle & Wells, 2011). Fundamental change is needed to deliver breaks in line with *what matters* to caring dyads (O'Shea, Timmons, O'Shea, Fox & Irving, 2019; Rochira, 2018).

Internationally, there is increased policy and practice interest in bespoke break options that help carers and those they support to realise outcomes important to

them. For example, the Integrated Carer Support Service (Australia), The Social Services Act (2010: 427) (Sweden) and the Lifespan Respite Care Reauthorisation Act of 2019 (USA). This reflects the transition of many economically developed nations towards personalised care and self-directed support. Descriptive accounts of bespoke break options for carers and PLWD in the literature include nature-based adult day services in the Netherlands (de Bruin, Buist, Hassink & Vaandrager, 2019), micro-care enterprises in England (Needham et al., 2015), houseguest programmes in the United States (Washington & Tachman, 2017) and creative arts and leisure programmes in England (Pienaar & Reynolds, 2015). However, research exploring the planning and commissioning arrangements underpinning their delivery is scarce (Seddon, Miller, Prendergast, Williamson & Cavaye, 2021), likewise, research demonstrating the outcomes supported through these breaks is limited (Henwood, Larkin & Milne, 2017).

In all UK regions breaks are commissioned within a specific policy and legislative context. In Wales, the Social Services and Wellbeing (Wales) Act 2014 (The Act) emphasises the importance of outcome focused provision to help people to achieve personal wellbeing outcomes. Carers have a legal right to a Carers' Needs Assessment (CNA), which is considered the primary route to access statutory breaks provision.

The Act further provides for seven Regional Partnership Boards (RPBs) which bring together public bodies, third and private sectors to progress the delivery of integrated services across Wales. The Integrated Care Fund (ICF) is the primary funding mechanism to deliver the requirements of the RPBs and is a key lever to encourage regional collaboration and embed 'innovation' in service provision (Welsh Government, 2021a). ICF carer programmes must support the delivery of the Welsh

Government's national priorities for Carers (Welsh Government, 2021b), including *a life alongside caring*, through breaks provision.

The research reported here explored factors shaping the planning, commissioning, and delivery of bespoke short breaks provision for spousal carers supporting a partner (aged 65+) with moderate to severe dementia in a region of Wales.

Method

Ethical approval was granted by the School of Healthcare and Medical Sciences Academic Ethics Committee (2019-16563), Bangor University.

Short break definition

In this research, a short break was defined as any form of service or assistance, which enables the carer(s) to have sufficient and regular periods away from their caring routines or responsibilities (Shared Care Scotland [SCS], 2017).

The study region

The study region has a distinct identity, underpinned by Welsh culture and language, and characterised by diverse topography, spanning rural mountainous regions to more populated coastal towns. The number of people aged 65 and over with moderate to severe dementia is expected to rise from 10,017 in 2020 to 16,361 in 2040 (National Social Care Data Portal for Wales, 2021). The local authority (LA) social services departments in the region have a statutory obligation to safeguard and promote the wellbeing of people who need care and support, and carers who need support. They work in partnership with organisations across the third and private

sectors to deliver a range of services to meet the care and support needs of their population.

Data collection

Between October 2019 and January 2020, purposive sampling (Palinkas et al., 2015) was used to identify 26 staff who participated in qualitative interviews. Two topic guides, one for strategic and one for operational staff, were designed in collaboration with a Project Engagement Group (PEG) that harnessed the expertise of professional stakeholders and ensured interview relevance to policy and practice directives. The distinct topics areas that guided the interview questions, for strategic and operational staff, respectively, are summarised in Table 1. All participants received a project information sheet (in Welsh and English) and formal written consent was gained. Ten interviews were conducted one-to-one and the remaining five in small groups ranging from two to four participants (Figure 1). Interviews were recorded and transcribed verbatim, anonymised, and stored in compliance with General Data Protection Regulations.

[Table 1]

[Figure 1]

Participant characteristics

The participant demographic consisted of staff working within the field of the health and social care. Participant characteristics by sector (i.e., third or statutory) and by role (i.e., operational, or strategic) are shown in Table 2. Strategic staff (e.g.,

Commissioning Officer) were identified as having responsibility for the commissioning and procurement of support services for carers. Operational staff (e.g., Social Worker) conducted CNAs and were involved in planning and delivering community support services that provided a short break.

[Table 2]

Data analysis

The software package Atlas.ti 8.2.34. (Friese, 2013) helped organise the data and facilitate data searching. The analytical process followed the methods for the heuristic coding, analysis and conceptualisation of data described by Braun and Clarke (2006) and Huberman, Miles, and Saldana (2014), respectively. Codes were generated through the reading of data, revisiting of data, and revising codes. Codes were then integrated to form patterns of data which represented potential processes and themes. These were then mapped to conceptualise the relationships between them, identify the different levels of data (e.g., overarching process and sub processes) and emerging contexts. The mapping of data to form an explanatory model of the short break landscape was an iterative process; key processes and contexts were reviewed and refined and aided the identification of contingencies involved in shaping the short break landscape. The verification of the model was supported through the PEG who commented on its cohesion and potential to inform planning and decision-making about short breaks provision.

Findings

An explanatory model of the short break landscape captures how staff described the current provision of breaks (Figure 2).

[Figure 2]

The model centres on a series of interlinked levels represented as

- 1) the core process
- 2) the local contexts
- 3) focal contingencies
- 4) wider contingences

A description of the explanatory models' levels is provided in Table 3

[Table 3]

A description of the data and illustrative quotes substantiates the model. Table 4 provides further supporting quotations. Quotes are coded as 'S' for strategic and 'O' for operational staff perspectives. A unique identifier is attributed to each participant.

[Table 4]

1. The core process

Operational staff spoke of the mutuality and reciprocity that imbued many caring relationships and emphasised that often carers require a break from their caring role and responsibilities rather than a break from their spouse. What constituted a bespoke, meaningful break varied considerably, from a carer "*who wants to go for a pint with his friends*" (O1), to a caring dyad who "*don't want to be split up but they*

want a break from being at home” (O6). Staff acknowledged that break needs and preferences evolved over time to reflect changes in the caring role associated with the progression of the dementia. For example, a preference for breaks taken together in the early stages that support engagement in community-based activities and, during the later stages of dementia, breaks that may involve temporary separation of varying duration through the provision of in-home or residential respite care.

2. The local contexts

2.1. Cultural context

Staff recognised that the generational distrust of social services held by some older carers fuelled anxiety and affected carers’ willingness to engage with statutory support, “*you do get people who initially will just say, “I do not want the LA knowing my business”*” (O9).

LA staff were therefore eager to “*re-educate what social services are about now*” (O3) to reflect how needs for a break are supported under the Act, i.e., meeting support needs should involve ‘building on people’s resources, including people’s strengths, abilities, families, and communities’ (Welsh Government, 2015, p. 13). Building carer independence from service engagement set the precedent for commissioned breaks provision, “*{Carers charity} are the support mechanism rather than the hand holder*” (S11).

Operational staff were mindful that the term ‘Carers Needs Assessments’ implied an assessment of ability to care, which many carers found intrusive. Considering this perception, the ‘What Matters’ (*Wales*) conversation was welcomed for its humanistic and holistic approach to co-producing break solutions; ‘What Matters’ is a discussion that reflects on carers’ lived experience and harnesses the

expertise of practitioners to explore carers' aspirations and any support required to achieve these;

“From a professional point of view, it’s much more satisfying. It has given more flexibility for carers to think of different ways that might work for them and there are opportunities there” (O6).

Operational staff discussed how caregiving was internalised by many spousal carers as a natural extension of their marital role. This moral duty to care explained, in part, why carers did not intuitively identify as a ‘carer’ in need of a break and would often *“struggle along, in that ‘we have to make this work’, the carer has this expectation of that ‘I am the husband or wife and I have to look after them’” (O1).* Loyalty to their identity and duty as a spouse meant the concept of a break was perceived as failure in their ability and dedication to care;

“[A short break] has to be under the radar to except, I think, because [carers] are so guilt ridden” (O9).

2.2. Care and support context

As well as the pronounced differences between communities across the study region in terms of language and culture, staff remarked on variations between LAs historic *modus operandi* that shaped the local outlay of breaks provision, *“In {LA} we are confident that we have recognised carers in a way that social care has been historically set up” (S5).*

One LA employed an Internal Carers Team who focused on supporting those facing particularly complex and challenging circumstances. LAs with a dedicated Commissioning Manager for carer services were juxtaposed to those with Commissioning Officers who oversaw service provision for carers of all ages *as well as* people living with complex health conditions. This enabled for a more coordinated

approach to commissioning short breaks provision, where the indirect effects of services for PLWD on carers and vice versa could be considered, *“we have to be extremely careful in how we put all our services together and mesh them, so people don’t fall through the cracks”* (S11).

The adult social care workforce was described as in *“major crisis”* (S9); high staff attrition was identified as a barrier to continuity of care and the development of carers’ trust in staff to deliver quality care and a meaningful break for their partner living with dementia;

“Carers worry while their partner is away because they are not satisfied and confident in the quality and it is not as good as being at home” (S6).

Operational staff reflected on the challenges of providing bespoke breaks in rural settings, where such provision was often deemed financially unviable. Rurality also affected the frequency of public transport which determined whether some carers could attend community activities that afforded them a break from caring.

3. Focal contingences

3.1. Developing equity of breaks provision across the region

Regional collaboration and use of the ICF. A regional Carers Strategy, developed through the RPB, agreed standards to support carers including improving the equity of access to flexible breaks. Under the RPB, the Carers Strategy Group expressed intent to develop a Short Break Toolkit that defined parameters for eligibility of entitlement to breaks across the region;

“There is a fresh talk about developing a tool to assess eligibility for short breaks and having some sort of equity across the board on that...it’s something we are going to look at regionally” (S4).

However, the degree to which regional intentions translated into practice was debated amongst staff. LA staff in a commissioning role recognised where local priorities and circumstances aligned, you could “*see the benefit of amalgamating and joining forces*” (S1) with neighbouring authorities. In such a context, the ICF supported a sub-regional contract to test a new model of delivering bespoke breaks;

“*{LA} have done it ten times better than we have, hence why we have gone for a collaborative approach*” (S8).

However, staff reflected on the lack of impetus to use the ICF to embed lasting change in how the region responds to the identified and crucial need to improve planning and commissioning for flexible breaks;

“*We have missed a trick...ICF funding is available for carers but we have all gone back and had our discussion on a local basis rather than having that regional discussion...we haven't had that regional dialogue*” (S1).

The Social Services and Wellbeing (Wales) Act 2014 repealed The Carers Strategies (Wales) Measure 2010, which placed the Local Health Board (LHB) as the lead agency in producing local Carers Information and Consultation Strategies. There was agreement from local authority and third sector staff that since the repeal of the 2010 Measure, there was a diluted sense of responsibility from the LHB for carers’ wellbeing and little systematic effort to ensure integration with breaks provision;

“*In the 2010 measure, there was a clear expectation of what LHB had to deliver...some LHB do some really great work, but it isn't necessarily that connected to local authorities*” (S13).

Effective coordination between local authorities and carers charities. The carers charities in the region work with the LAs. Third sector staff observed that

where there was effective coordination and communication with a LA (i.e., team working, data sharing agreements, and commissioning strategies that harnessed the local knowledge of charities), breaks needs were supported in a more efficient and resourceful way;

“The Carers’ Officer can go straight to the carers’ house and phone me from there and say, ‘I’m with this carer now, what can you offer’ and can we be there tomorrow or next week. Everywhere else it must go through different stages before you can get there, the carer might be waiting six weeks for a break” (O8).

Strategic staff within LAs commented that commissioning a carers charity to conduct CNAs established a clear and single process to access a break and afforded greater confidence and assurance for carers to know they had an independent assessment. Similarly, the commissioning of breaks provision to carer charities was premised on their capacity to “do more with less money” (S12), and ability “to continue to be creative about providing services and giving [carers] a short break” (S14) tailored to their personal circumstances; they were championing the planning and delivery of bespoke breaks.

3.2 Building resilient and inclusive communities

Supporting choice and diversity of breaks. To promote diversity and choice of break activities, staff spoke of the need to facilitate breaks with sectors involving the environment, arts, sports, leisure, tourism and hospitality;

“We are looking at a woodland project, rather than traditional day care...we are hoping people can use their support budgets to pay for something like that. A lot of people say they want fresh air, they want to be outside” (O6).

There was strategic interest from LA staff in community break activities (e.g., peer support groups, coffee mornings, luncheon clubs, exercise groups etc) that could become self-sufficient in terms of governance and funding with minimal reliance on statutory social care provision;

“The community itself is really coming behind that project and they’re getting legacies from wills... it’s that balance between something that was started by the LA but is taking momentum within the community” (S9).

Carers charities were eager to scale up their respite offer (i.e., partnering with hospitality, tourism and leisure businesses willing to donate a break, free of charge or at a discounted rate). Local respite provision included hotel breaks, spa weekends and caravan holidays, and presented a choice for the caring dyad to experience a break together or apart. Where the carers charity organised a group hotel or spa break, staff would accompany, organise transport and be there *“if they need to talk to somebody”* (O7). Group breaks also encouraged social interaction and peer support between those in similar caring circumstances;

“Carers are so grateful they have had two nights away, but they have also met other people...some have set up Facebook groups and have met up” (O7).

Connecting carers to Information, Advice and Assistance (IAA). To empower carers with the information to make an informed decision about the break options available, strategic staff in LAs emphasised having *“more information locally, down there on the ground... this is what we need our communities to be like”* (S11). Within each LA there was praise for the work of staff (e.g., Community Connectors) embedded within the community who provided relevant and timely IAA, and crucially, helped carers make sense of the information and signpost to short break opportunities;

“They connect people to whatever is in the community in terms of services, local opportunities, social groups and work closely with {carer’s charity} who is the main provider of short breaks” (S1).

LA staff mentioned developments to their online IAA services, including carer information packs and essential guides, detailing who to contact to request a CNA, different ways a break maybe achieved and a list of organisations that may support breaks.

Normalising breaks through carer friendly communities. Alongside momentum to develop dementia friendly communities, staff articulated the importance of cultivating carer friendly communities, where local communities and their residents of all ages and cultures would legitimately recognise carers’ needs for a break;

“We need to work with communities better...so the carers know that if their loved one wants to go to the pub somebody is there and if they are having difficulties the carer will get a phone call” (O6).

In addition to peer support groups exclusive to carers and/or PLWD, staff articulated a vision for community activities that were *“more inclusive of everybody who wants more support”* (S9), and therefore appealed to those *“reluctant to label themselves as carers”* (S9).

Volunteers were central to galvanising change and championing PLWD to be supported to remain active and visible within their community, which could allow carers to have a break (jointly or separately from their spouse).

3.3 Understanding ‘what matters’ in breaks provision

Characteristics of a bespoke, meaningful break. Staff identified

characteristics of provision that supported a bespoke, meaningful break experience for the caring dyad:

- choice in breaks to align with personal preferences (e.g., the caring dyad can experience a break together or separately);
- flexible provision (i.e., regular provision balanced with a break ‘as and when needed’);
- ability to plan a break in advance;
- consistency of break provider/care staff to establish a trusting caring partnership;
- appropriateness of the break to the person’s stage of dementia and tailored to their interests, to support meaningful engagement;
- sustainability of provision so the benefit is cumulative.

Across the region, new models of break provision embedded some of these characteristics and were being piloted. Examples included Care Co-operatives (pooling support packages for caring dyads with similar needs and interests), personalised support schemes, such as Shared Lives, micro-care enterprises (i.e., small businesses of up to five people who offer flexible and personalised care and support services) and volunteer-led services;

“The {personalised support scheme} is a great idea if it will take off. I have loads of people in my case load who need that one-to-one support and to be taken places of their interest... it will help so much with reducing carer breakdown”
(O2).

Acknowledging the merit in the ‘traditional’. The consensus amongst staff was that ‘traditional’ services (i.e., day care, residential or in-home respite) maintained a valuable place within the spectrum of breaks provision;

“One of the ladies whose husband would come to {residential home} before Christmas, she would get the house sorted out and get her head straight and it made all the difference to them... I remember saying we’re going to close... both of their faces just dropped” (S7).

Day and residential respite care which provided meaningful occupation for the PLWD (e.g., intergenerational programmes, links to community activities) and had invested in dementia training for its staff were considered an asset; *“We have got the formal day care centre in {Town} which I think is an invaluable service” (S1).*

Staff emphasised that the preference of people with advanced dementia to remain within a familiar environment meant in-home respite was an essential break service, *“PLWD tend to like routine and their surroundings, if they go somewhere totally new, it would compound confusion possibly” (O10).*

4. Wider contingencies

4.1. The ICF directive to innovate

Staff reflected that the ICF directive to ‘innovate’ risked the consistency of breaks provision in favour of new projects that evidenced ‘additionality’;

“I’m always writing bids and you must tick the innovation box, but actually what I want to say is ‘we want to continue with this effective project, it has been working well’. You can’t do that; it has to be blooming innovative” (S7).

Staff reported that carers value reliability and continuity of breaks provision. What ‘works’ and what is meaningful does not always equate to something new and

‘innovative’, “*they are simple services that don’t need to be changed every year*” (S13).

4.2. Funding cycles and structures underpinning the Act

All staff expressed concern over reducing public funds and the pressure to make savings. The need to be “*to be rational and careful*” (S5) with available resources meant difficult commissioning decisions;

“*It’s half the money they used to give... It’s hard...sometimes you must make the decision whether to give fewer people a real meaningful break or give more people less*” (O12).

LA strategic-level staff agreed that the ‘short-termism’ of funding cycles made it difficult to invest in stable and effective partnerships with third or private sector short break providers.

“*It takes trust, it takes investment...the funding practices don’t encourage sustainability. They don’t encourage the retention of a specialist workforce*” (S13).

Third sector perception of gaining access to the ICF was described as “*an old boys club...we can’t get in*” (S7) and the tendering process as disheartening and overly bureaucratic.

A third sector Chief Executive discussed the challenge of utilising small amounts of funding, awarded through various streams, so all carers within the authorities that they operate, had similar break opportunities;

“*{LA} will give us a set amount, and {LA} a different amount from {LA} and yet we want to be able to offer the same services to all the carers in the area which means I have to apply for funding from different places to make sure there is equity of service for all the carers*” (S14).

4.3. The Act's requirement to involve carers and PLWD in shaping breaks provision

Different methods were used to involve carers and PLWD in the shaping of breaks provision. Locally, these included carers' forums, viewpoint meetings, case studies of CNAs (process and outcomes), questionnaires, and surveys.

Voluntary Councils and smaller not-for-profit organisations nested within communities were considered "*better placed to talk to people about their growing needs, they know the people within their community*" (S9).

At a regional level, a formal requirement of the RPB is to conduct a Population Assessment which includes the assessment of carers' needs for support. However, concern was expressed by third sector staff, that it was often the voices of the same demographic of carers, active in their community and 'easy to access' which were captured in this assessment. Yet, the voices of carers in most need of a break, but who could rarely leave their house because of their intensive caring responsibilities, and therefore less visible in their community, were absent.

4.4. Determining eligibility for short breaks

Strategic staff reflected that whilst the Act recognises the importance of a CNA to identify, understand and evidence short break needs, stringent eligibility criteria means that, "*lots of people are getting an assessment and nothing happens anyway... it's just an exercise and they may or may not get services*" (S4).

This meant staff conducting CNAs needed to be creative in employing people's strengths, families and communities in supporting a break;

“Unless someone is really in crisis, I’m quite often asked to look at community things, can the cared for go to a group that is community based so we don’t fund it...I’ve a gentleman who doesn’t want to leave the house so it makes it difficult” (O1).

Staff conducting CNAs underlined the need for diplomacy to support compromise where the caring dyad diverged in their perspective of the caring situation or in break preferences, and likewise, to address where a personal financial contribution may support a break;

“One of the things that is challenging following from the Act, is emphasis on ‘what am I able to do for myself or bring to the table’ ...you may have the resources to be able to provide the respite you are seeking without any intervention from social care” (S5).

Discussion

This paper presents a model of the short break landscape in a region of Wales, highlighting key factors shaping short breaks provision. The model supports the translation of challenges and opportunities associated with the planning, commissioning, and delivery of bespoke short breaks to progress policy discussion and increase practice wisdom. Through highlighting complex context-specific processes and contingencies, the model contributes towards preliminary theory development of *what works and under what circumstances* in short breaks provision.

Findings highlight the strategic challenge in achieving equity of access to flexible breaks throughout the region. Notwithstanding the value of the RPB in regional strategy development, there is limited detail to show how intent for equity of flexible breaks is operationalised and its effectiveness evaluated at a local level. The

National Assembly for Wales, Health, Social Care and Sport Committee has called for stronger leadership from the Welsh Government to work with RPBs to achieve greater consistency in support services, unify and refine reporting mechanisms across regions in Wales (National Assembly for Wales, 2019).

The challenges associated with scarce funding and resources underlies the need for evidence informed commissioning to ensure model/service effectiveness. At minimum, future investment in bespoke break models should consider their degree of contribution towards national wellbeing outcomes for carers, PLWD and for the caring relationship, including where feasible, the capture of proximal and distal outcomes. Alongside contribution to wellbeing outcomes, the demonstration of cost effectiveness or Social Return on Investment (SROI) provide compelling economic evidence for policy makers and commissioners surrounding the costs and benefits of short break provision (Kirk & Kagan, 2015). In Wales, new research is establishing the utility of SROI analysis, a form of cost-benefit analysis, as a method to evaluate an alternative to day centre support for PLWD and their families (Toms, Seddon, Edwards & Jones, 2020).

Opportunities identified through this research relate to the potential for LAs and the third sector to work collectively to engage and involve carers at different stages and levels of caregiving, and where feasible PLWD, to harness their lived experiences and embed this knowledge in planning breaks. Good practice can be drawn from the Shared Care Scotland Short Break Consultation Toolkit (SCS, 2020) which exemplifies a variety of adaptable tools for varied settings and stakeholders to generate ideas and gather information to prioritise decision-making.

There is scope for LAs to buoy the strengths of carers charities, who were the notable pioneers of bespoke breaks. Reflecting the emerging interest in respiteability

orchestrated through carer charities, important lessons for the scale up, governance and quality assurance of respitality models can be learnt from SCS. In Scotland, respitality operates as a social franchise; models of respitality are managed by local carer organisations and coordinated and supported nationally by SCS.

A limitation of this research is the absence of health professionals and representatives from private short break providers; insight from these sectors would enrich current findings. In addition to addressing the gaps in professional insight, to allow for an integrated perspective, the next phase of research will seek the views of carers, and where possible PLWD, in accessing breaks provision and enable comparison and synthesis with the current representation of the short break landscape.

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Table 1

Areas of substantive interest addressed in interviews

Strategic areas of interest

Meaning of ‘innovation’ in relation to the commissioning and/or delivery of breaks

Barriers and facilitators to the scaling up of bespoke, meaningful breaks provision and sustaining over time (including structures, resources, practices, and processes)

Translating the legal duty to promote a variety of providers into practice to respond to the diversity of break needs and preferences

Vision for the evolution of commissioning and/or delivery arrangements to address local and regional priorities in relation to breaks provision

Use of resources to support the delivery of Welsh Government national priorities, especially *a life alongside caring*

Evidence most compelling in steering future commissioning

Opportunities to learn and share good practice across the region

Involvement of carers and people living with dementia in the planning and shaping of breaks provision

Over the next five years, the greatest challenge and/or opportunity to meet the growing need for breaks provision

Operational areas of interest

What matters most to carers about breaks provision

Strengths and weaknesses of current breaks provision

Barriers and facilitators for caring dyads to access a break

Ways to empower carers with choice and control in relation to breaks provision

Extent to which break needs and preferences are identified, discussed, and evidenced during Carer's Needs Assessments

Over the next five years, the greatest challenge and/or opportunity to meet the growing need for breaks provision

Table 2

Participant characteristics by sector and role

	Role		
Sector	Strategic	Operational	Total
Third	3	6	9
Statutory	11	6	17
	14	12	26

Table 3

Description of the explanatory model's levels

1. The core process

Represents the dyadic nature of caregiving and acknowledges the interdependencies that exist between the caring dyad, their values and preferences and the stage of dementia in shaping *what matters* in short breaks provision.

2. The local contexts

2.1 Cultural context

The perceptions, morals and beliefs that influence carer's engagement with support provision, sense of duty to care for their partner living with dementia and self-identification as a 'carer'.

2.2 Care and support context

The local circumstances that shape short breaks provision (e.g., the adult social care workforce, rurality, and local authority operational and commissioning arrangements).

3. Focal contingences

Characterised by three key interlinked processes occurring at a local and regional level; 1. developing equity of breaks provision across the region, 2. building resilient and inclusive communities, 3. understanding '*what matters*' in short breaks provision. These processes shape the manner and means to which breaks provision is supported across the region. They also play a part in facilitating the steps needed for effective collaboration between sectors and supporting the vision for inclusive communities to reduce social isolation and stigma of living, or caring, for someone with dementia.

4. Wider contingences

Represent the extent to which policy ambition and legislative requirements exert influence on local and regional decision-making in relation to short breaks provision.

Table 4

Supporting quotations

1. The core process	<i>“It’s understanding the carers’ needs, their wants, their desires, but also how that can they be negotiated with the cared-for...we have to look at it in the context of the whole picture and that is when it becomes even more personalised as a result”</i> (S5)
2. The local contexts	
2.1 The cultural context	<i>“In my experience, carers tend to wait until they are really under strain and then ask for help. I think they could do with a bit more of a push in getting people involved sooner, it tends to be carers in crisis that we go out to assess”</i> (O1)
2.2 The care and support context	<i>“In each local authority the areas are different and the people they are working with are very different. In {local authority}, they have many little services for carers, and they have their own Carers Officers, {local authority} and {local authority} do not”</i> (S14)
3. Focal contingences	
3.1. <i>Developing equity of breaks provision across the region</i>	
Regional collaboration and use of the ICF	<i>“I’m not convinced that regional carers’ plans are as connected as they should be. I think there’s a need when funds have been spent that there is better monitoring and evaluation at a regional level of how we’re defining what services are needed”</i> (S13)

Effective coordination between local authorities and carers charities *“We have strengthened our relationship with the third sector...I can definitely see improved relations in terms of co-ordinating of services, the third sector working together more” (S1)*

3.2. Building resilient and inclusive communities

Supporting choice and diversity of breaks *“There are other things we have been doing with IFC for example the mindfulness courses we have put on for carers. We did a pilot for carers of people living with dementia...in terms of giving carers a toolkit if you like, to boost their resilience... it was evaluated so positively” (S4)*

Connecting carers to IAA *“We find that the Local Asset Co-ordinators are working well with informal carers... if things get tough, [carers] have that contact with the Local Asset Co-ordinator who works closely with our Social Workers here... it brings everything together and I think that early intervention, having information at the right time and in the right place is key” (S1)*

Normalising breaks through carer friendly communities *“Carers have to feel confident to take their loved one out because if something happens at home, no one sees anything, people don’t feel embarrassed, but people don’t really know how people are going to react out there” (S9)*

3.3 Understanding ‘what matters’ in breaks provision

Characteristics of a bespoke, meaningful break

- Choice in breaks to align with personal preferences *“Many carers feel guilty about putting their loved one in day care because they are not doing anything, they are just sitting, and the telly is on. Although they need a break, they are not benefiting from that break because they are thinking about them all day” (S12)*

<ul style="list-style-type: none"> • Flexible provision (i.e., regular provision balanced with a break ‘as and when needed’) 	<p><i>“Sometimes the local authorities can’t be flexible with their system so they may say Miss Jones wants three hours every Monday, 10am – 1pm, but actually Miss Jones doesn’t want that...she will tell us, mostly I would like it, but I would like to be flexible. I would like to save it sometimes and have a whole day out” (S13)</i></p>
<ul style="list-style-type: none"> • The ability to plan a break in advance 	<p><i>“For carers they can’t plan ahead, and they want to be able to, so moving that respite care from crisis or managing hospital appointments for the carer, to a space where respite is about planning positive things that they could look forward to with or without the person they care for” (S14).</i></p>
<ul style="list-style-type: none"> • Consistency of break provider/care staff to establish trusting caring partnerships 	<p><i>“I think it helps people to have the continuous contact with the same person and the same organisation that know their story, so they don’t have to start from the beginning...[carers] are building up a relationship with that support worker and so is the person with dementia” (O8)</i></p>
<ul style="list-style-type: none"> • Appropriateness of the break to the person’s stage of dementia and tailored to interests, to support meaningful engagement 	<p><i>“There are great groups going on but when the person with dementia deteriorates, they can’t go anymore...that happens a lot with day care, they say people with dementia become too disruptive and too challenging and they haven’t got the staff and then the carer has nothing” (O8)</i></p>
<ul style="list-style-type: none"> • Sustainability of provision so the benefit is cumulative 	<p><i>“We have a carer, she was given a small amount of funding for respite and she started going line dancing, doing what she wanted to do, but after the six weeks she couldn’t go anymore. We know there is issue with money but that is really affecting her that she cannot go. That is a big barrier; things are only for a set amount of time” (O9)</i></p>

Acknowledging the merit in the
'traditional'

"Obviously there has been a shift in thinking about a day centre, in a sense of, we all have that image of a day centre, the TV on in the corner and nobody doing anything. I think {day care centre} is very good at trips going out and things going on" (S2)

4. Wider contingences

4.1. The ICF directive to innovate

"There is always a risk isn't there, the pressure is to always be 'innovative' because the expectation is to innovative, but you run the risk of throwing out what works really well because it's not the current thinking" (S5)

4.2. Funding cycles and structures
underpinning the Act

"In an ideal world it would be nice to be able to give three-year contracts, with an option to extend to two, but there is a risk perhaps in that we are moving towards an annual grant-based cycle of funding, obviously you have got staff retention issues with providers and high staff turnover as a result" (S4)

4.3. The Act's requirement to involve
carers and PLWD in shaping breaks
provision

"Is this still working for the community? We have a participation team that runs behind this, that can go and speak to those who are receiving services and ask are we getting it right, have we completely understood what your needs are?" (S5)

4.4. Determining eligibility for short
breaks

*"It's all very well **us** telling somebody that you have to pay towards something, but at no point did the Welsh Government mention that you might have to contribute and think about what your own assets are"* (S5)

Figure 1

Frequency of interviews by group size

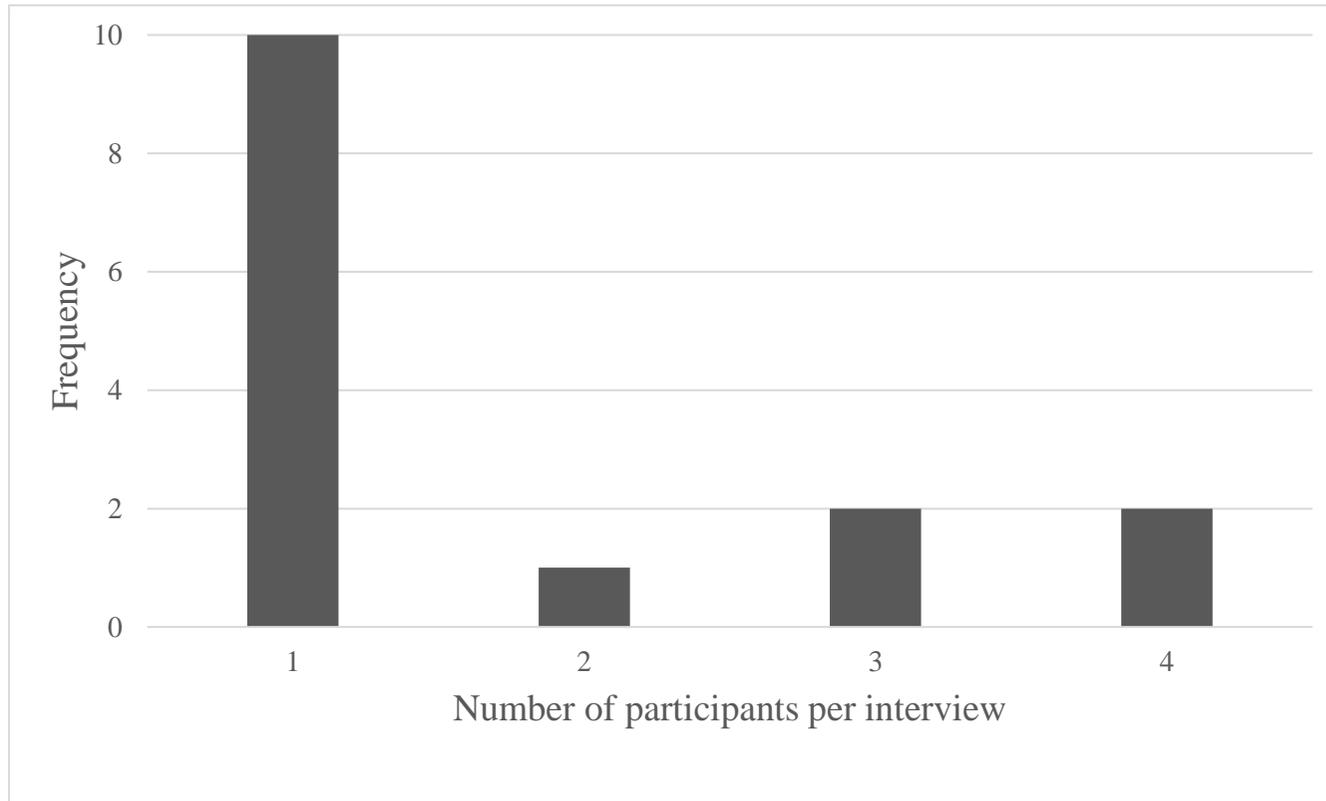


Figure 2

An explanatory model of the short break landscape

