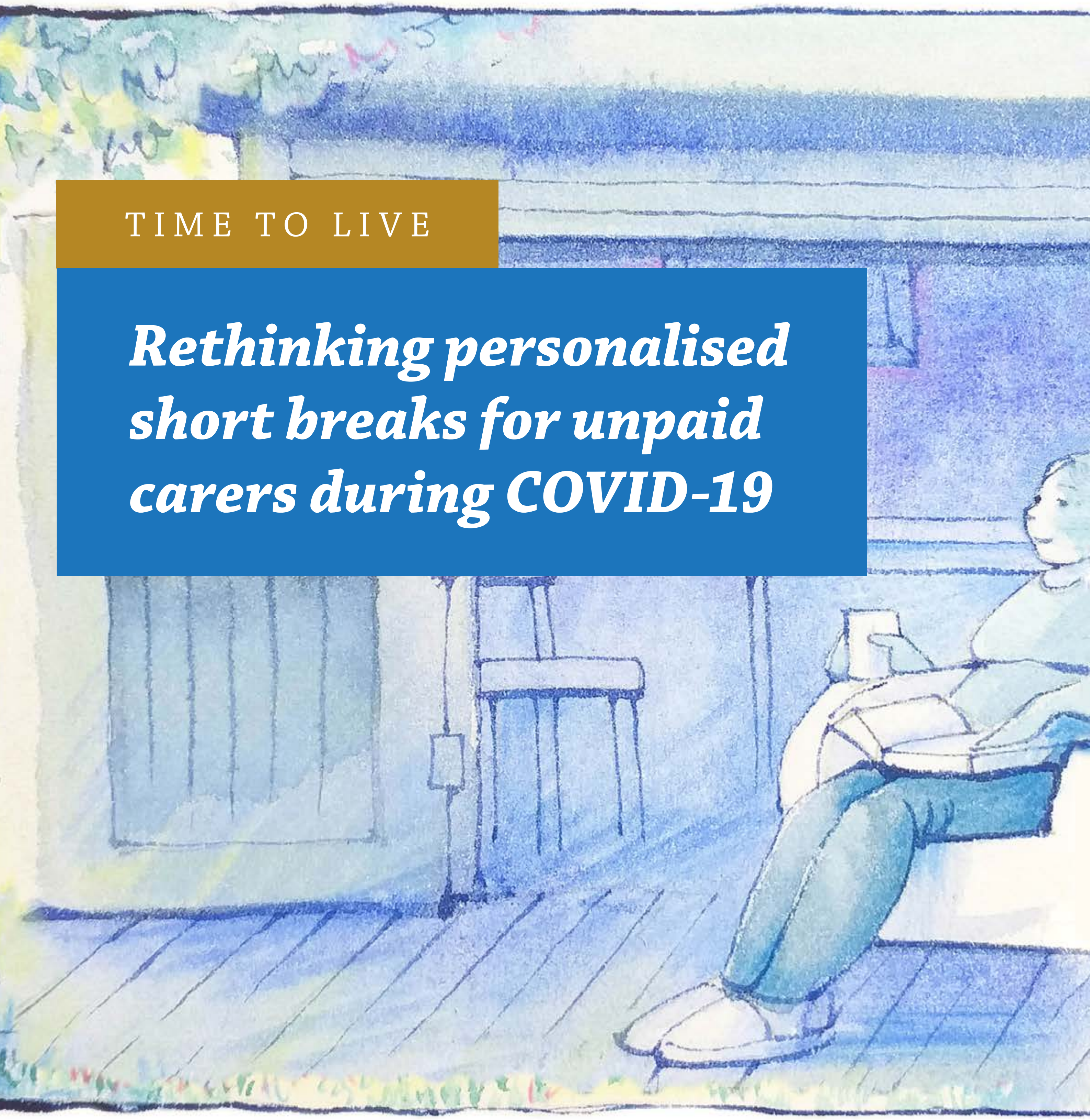

TIME TO LIVE

Rethinking personalised short breaks for unpaid carers during COVID-19

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Foreword

The name of our grants programme, ‘Time to Live’, was conceived by a carer who used this expression to convey their wish to have some time in their life for activities that fulfilled them, and that helped them to enjoy and appreciate life. Of course, for many carers finding time, or as the report refers, ‘pockets of respite’, can be extremely difficult.

The stories contained in this report are a powerful reminder of the importance of breaks from caring

The stories contained in this report are a powerful reminder of the importance of breaks from caring, and the importance of carers having breaks that they have control over. As well as helping carers to rest and recharge, the report reveals how breaks contribute to a strengthened sense of self, associated with being supported to enjoy personal interests that are outside the ‘caring world’. The report also provides many examples of creative ways breaks can be achieved and woven into day-to-day routines.

While Time to Live funding helps enable these personalised breaks, it is clear from this research that good conversations and trusted relationships are the essential ingredients that ensure carers are supported to achieve the best possible outcomes from the funding available. For this, we must express our gratitude to all the Time to Live delivery partners, and their dedicated staff and volunteers, who, since Time to Live launched over 11 years ago, have supported tens of thousands of carers to find the break that works best for them. This report is a tribute to their efforts.

We hope this research provides further evidence to support the case for all carers to have the preventative breaks they need to be able to balance caring with other things that are important in their lives. After all, all carers deserve ‘time to live.’

Our sincere thanks to Andreea Bocioaga and Ellen Daly at Iriss, and to all the carers and carers centre staff who contributed to this research. Our thanks also to the Scottish Government for their continued support of Time to Live.

Don Williamson

Chief Executive, Shared Care Scotland

1. Executive summary

Shared Care Scotland commissioned **Iriss** to provide them with timely, robust information about the impact of the Time to Live (TtL) grant scheme on unpaid adult carers' personal outcomes during the COVID-19 pandemic. Evidence about barriers and enablers for carers in accessing TtL grants and the experience of carer centres as delivery partners of managing TtL grants during the pandemic was also gathered. Eighteen interviews took place between October and December 2021: twelve with carers, six with carers centres. This report explores key areas in relation to the impact of TtL short breaks on carers' personal outcomes and sustainability of the breaks. The report also examines the processes that underpin these breaks, including how centres promote TtL funding and how they identify and record outcomes.

PERSONAL OUTCOMES

Carers used their TtL grants in various ways and the breaks were personalised to each individual's circumstances. There were contextual similarities to the breaks as a result of COVID-19, for example most of the breaks were taken at home and involved adding something to the home environment. This report identifies a range of personal outcomes that the breaks supported. Some of these outcomes are derived from the overall support process itself and relate to increased access to other kinds of help, reduced isolation and reduced administrative burden. Carers also identified financial wellbeing, physical and mental wellbeing, improved relationships and a strengthened sense of self as key personal outcomes that were supported through their short breaks.

SUSTAINABILITY

The support provided by carers centres encouraged carers to focus on activities with lasting benefits over quick fixes. Most carers chose to use their funding on activities that could be taken over a longer period of time (e.g. massage vouchers, yoga classes) or on equipment with long-term use, embedding 'pockets of respite' into their everyday lives.

Where short break activities involved learning new skills, carers talked about their interests expanding into other areas as their expertise improved. Perhaps most importantly, short breaks enabled carers to keep going in their caring role during an incredibly stressful time.

PROCESS AND PROMOTION

Carer centres take different approaches to promoting the fund – some allow for direct applications while others apply with or on behalf of the carer. Carers centres also have to negotiate the constant tension between supply of funds and demand from their carer population which involves different approaches to offering repeat breaks. COVID-19 also highlighted the need to ensure that carers who have limited digital access are not excluded from applying for short break funding.

Support workers seek to have conversations with carers which focus on their identity and explore personal outcomes to help choose the right break. Managers feel that reporting is supported by the TtL principles (see appendix 2) which help structure their reports and align well with their organisational vision, values, local policies and procedures. Some centres also seek extra rigour for their evaluation processes in the form of external assessors.

FUTURE FOCUS

Lastly, this report highlights key findings in relation to carers’ experiences of short breaks, personal outcomes and the organisational processes that underpin the delivery of the TtL grant. These points provide useful insights to inform development and improvement activities relating to the TtL grant.

2. Introduction

TIME TO LIVE

Over the past ten years, Shared Care Scotland has administered the Time to Live (TtL) grants programme, one of four grants programmes that make up the Short Breaks Fund. The Short Breaks Fund of £3m is funded annually by the Scottish Government. Approximately £500k of this is allocated to TtL. The programme provides 12-month grants to carers organisations (usually carers centres) to develop and deliver micro-grants schemes for carers of adults (aged 21 years and over) and young carers (caring for children or adults). These TtL projects enable carers to access funds and support to help have some time away from their 'caring world' to pursue personal interests and activities that they enjoy, and contribute to their health and wellbeing.

The grant is calculated based on how many carers reside within a local authority catchment area, with an additional premium made available to those delivering services in remote and rural areas, to take account of other costs of providing services in those areas.

The primary outcomes the TtL programme aims to achieve are:

- Carers will have improved wellbeing
- Carers will have more opportunities to enjoy life alongside their caring role
- Carers will feel better supported to sustain their caring role

Short breaks funded through TtL fall into five categories:

- Traditional holiday-type short breaks (trips requiring an overnight stay away from the caring situation)
- Short breaks receiving services (e.g. a massage or alternative therapy)
- Short breaks receiving equipment (e.g. bikes or computers)
- Short breaks receiving space (e.g. a shed or a greenhouse)
- Short breaks receiving time (e.g. driving lessons to shorten travel to the caring role, makes time available for a short break)

Typically grants are in the region of £300 and each delivery partner is responsible for administering its processes for receiving and deciding on applications.

Throughout the COVID-19 pandemic, TtL grants have been used to support carers to have breaks at home or close to home. This support has been critical to those carers who were shielding and whose caring role intensified due to the suspension of their routine care support services, including respite care. £930k of extra funding was provided by the Scottish Government to expand TtL support during this time, including extending the fund to include parent carers.

KNOWLEDGE GAPS

There are gaps in the evidence about the impact of providing this direct support to carers to help maximise the positive outcomes from periods of respite. Most research has focused on the ‘replacement care’ activities, which are services for the cared-for person and provide a respite effect for the carers by giving the carer timeout from their caring responsibilities.

A recent scoping review commissioned by Shared Care Scotland (Seddon and Prendergast, 2019) acknowledged that ‘there remain significant gaps in our understanding of the impact of short breaks provision, particularly the impact of alternative short breaks that move away from traditional service models’ (p21). The paper highlighted three priority lines of inquiry:

- Understanding what matters – capturing and evidencing short break needs
- Capturing what matters – outcomes from short breaks
- Commissioning, delivering and scaling up alternative short breaks provision to reflect what matters to carers

This research study was commissioned to help address these knowledge gaps by gathering stories from carers and delivery partners about how personal outcomes were identified and supported by TtL grant funding through the COVID-19 pandemic. Personal outcomes are defined as what matters to people accessing support and their unpaid carers. A particular area of interest is on understanding how TtL grants have helped carers consider their outcomes and if grant funding has been a catalyst for carers to pursue hobbies, interests, and other activities that contribute to good health and mental wellbeing. With this in mind, the following aims, objectives and research questions were developed…

AIMS

This research aims to provide Shared Care Scotland with timely, robust information about:

- Evidence of the impact of the TtL grant scheme on adult carers' (16 years +) personal outcomes during the COVID-19 pandemic (from April 2020 – present)
- Barriers and enablers experienced by carers in accessing TtL grants
- Experience of carer centres as delivery partners of using TtL grants during COVID-19

OBJECTIVES

To meet the aims, the specific objectives of the project are:

- The clear identification (from analysis of relevant policy, research and interview data with carers) of how the TtL grants supported the personal outcomes of carers' during the COVID-19 pandemic including:
    - » How carers used their time to maximise positive outcomes
    - » Ways in which the TtL grant 'opened the door' to other activities that contributed to sustaining good health and mental wellbeing
- To identify barriers and enablers in the process of accessing TtL grants for carers
- To gather evidence to inform delivery partners and Shared Care Scotland on how to promote the benefits of TtL and optimise support to carers to help them sustain activities where TtL has been the catalyst
- To provide insights to Shared Care Scotland to inform proposed options and recommendations for the future of TtL / other micro-grants schemes

RESEARCH QUESTIONS

CARERS

- Impact: How has the TtL grant supported carers to meet their personal outcomes during the COVID-19 pandemic?
- Sustainability: To what extent are TtL grants supporting carers to achieve a more sustainable balance between caring and other things they want in their lives?
- Process: How did carers experience the process of accessing the TtL grant?

CARERS CENTRES

Promotion: How do centres currently promote TtL? Are there particular groups of carers that they feel they are not reaching?

- Identifying outcomes: How do centres work with carers to identify what's important to them / their personal outcomes?
- Recording outcomes: How do centres capture whether these outcomes have been achieved as a result of the TtL grant? How do centres find applying the five principles of the TtL grant? (see appendix 2)

3. Methodology

This research involved a mixed-method approach, including desk-based research and stakeholder engagement.

DESK-BASED RESEARCH

A rapid review of relevant policy, legislation and existing evidence was produced in order to provide background and context (see appendix 1).

IDENTIFYING PARTICIPANTS

CARERS CENTRES

Shared Care Scotland identified six carers centres to participate in the research from urban, rural and remote areas of Scotland. Centre managers were invited to take part in an interview, and to identify carers who would be willing to share their story with the project researchers. Centres were asked to identify carers from a mix of backgrounds and genders.

CARERS

Each of the six centres identified two adult carers (16 years and over) that had received a TtL grant since April 2020. A data-sharing agreement was drawn up between Iriss and the

centres to allow the sharing of carer contact details with Iriss for the purpose of arranging an interview. Carers were offered vouchers of their choice or cash to the value of £20 as compensation for their time.

It became apparent that the carers identified by carer centres for interview were mostly female. This could be due to various factors such as demographics, existing relationships and accessibility. To counter this the researchers asked two carer centres to prioritise male carers which resulted in two being invited to interview.

Two carers identified for interview were from a BAME (Black, Asian and minority ethnic) background.

SEMI-STRUCTURED INTERVIEWS

Eighteen interviews took place between October and December 2021; twelve with carers, six with carers centres. Four of the six interviews with carers centres included a manager and at least one support worker. Two carer interviews were joint – one with a couple, one with a carer from a BAME background and her support worker who translated.

Interviews were conducted remotely, using phone and video calls. Where possible, interview questions were shared ahead of time. Each interview was audio-recorded and transcribed. An information sheet and consent form were shared with interviewees ahead of time.

ANALYSIS

Each transcript was comparatively analysed using secure data analysis software and was coded to extract commonality and themes, as well as highlighting areas of importance to Shared Care Scotland and delivery partners.

CARERS' STORIES

Interview transcripts were used to develop stories. These are in carers’ own words with minor edits and sequence changes. Names have been changed to protect anonymity. The focus of the stories is on the difference the short breaks made to carers’ personal outcomes. Quotes from interviews and stories are weaved through the report, with full versions available in a seperate *Carers' Stories* publication that can be found on the **Shared Care Scotland website**.

SUMMARY: CARER PROFILES, HOW TTL GRANTS WERE USED AND PERSONAL OUTCOMES SUPPORTED

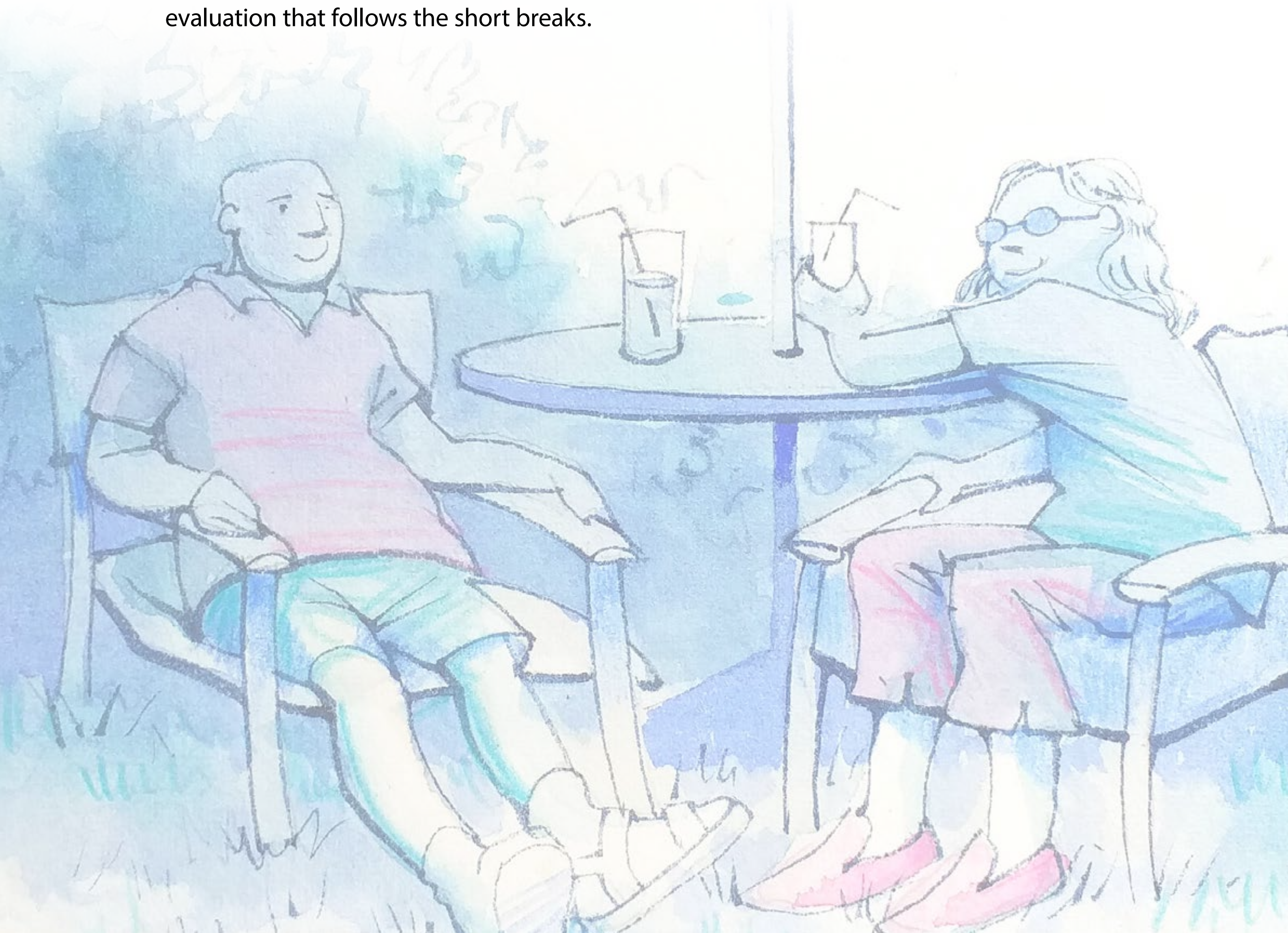
Carer	Context: cared-for person(s), length of time caring at time of interview, living situation	Previous experience of short breaks	How TtL grant(s) was used	Personal outcomes supported from the short break
Aleena	Cares for her mother-in-law and her daughter for the last nine years. Cohabiting in an urban area.	First short break	Yoga classes	• Health and wellbeing • Financial wellbeing
Anna	Cares for her husband for the last six years. Anna was a carer for her mother before that. Cohabiting in a small village.	Seven years since last short break	Garden chairs A short break away	• Health and wellbeing • Stress relief • Something to look forward to / anticipation
Audrey	Cares for her son for the last 14 years. Cohabiting in a rural area.	Usually accesses Family Fund. Son receives three nights a month respite	A trampoline	• Health and wellbeing • Financial wellbeing • Improved relationships
Frances	Cares for her adult son for the last 20 years. Cohabiting in a rural area.	First short break	A tent	• Health and wellbeing • Keeping busy
Isabelle	Cares for her brother and her parents before that. Isabelle has been a carer since she left school. Lives separately in a town.	Four years since last break	Diamond paintings	• Mental wellbeing
Lynn & Neil	Cares for their two children for the last 12 years. Cohabiting in a rural area.	Three years since last break	A short break away	• Health and wellbeing • Stress relief • Improved relationships
Margaret	Cares for her husband for the last three years. Cohabiting in a village.	Two years (approx)	A shed	• Mental wellbeing • Strengthened identity
Maria	Cares for her mother. Maria has been in a caring role since she was a child. Cohabiting in an urban area.	Annual short breaks for the last four years	Nail equipment	• Financial wellbeing • Self-care • Learning new skills • Strengthened identity • Improved relationships
Mark	Cares for his wife for the last four years. Cohabiting in a remote area.	First short break	A garden bench	• Health and wellbeing • Financial wellbeing • Improved relationships • Reduced social isolation • Strengthened identity
Megan	Cares for her daughter, nephew and niece for the last four years. Sporadic cohabiting in a small town.	Previous short breaks in 2018 & 2020	Arts and crafts supplies	• Mental wellbeing
Nina	Cares for her mother for the last year. Nina has been her mother's carer on and off for many years. Cohabiting in a rural area.	First short break	A greenhouse	• Health and wellbeing • Financial wellbeing • Strengthened identity • Improved relationships • Learning new skills
Rania	Cares for her mother for the last seven years. Lives separately in an urban area.	Two years since last break	Massage vouchers	• Health and wellbeing • Financial wellbeing • Improved relationships

Findings

The following sections explore the key findings of this research.

The first section is focused on carers' experiences and personal outcomes. First, we consider the carers' experiences of the breaks and the impact this had on their lives. This includes the different kinds of outcomes that are supported through short break funding. Then we discuss how the breaks impact the sustainability of the caring role and consider sustainability more broadly in relation to short breaks and wellbeing. Lastly, we consider the overall support process that carer centres provide and how that relates to specific outcomes for carers.

The second section explores the processes that carers centres have in place to manage, promote and distribute the TtL grant. We consider how centres manage the money, which carers are hard-to-reach and how centres are attempting to counter these gaps. Following this, we discuss the support process itself, including how carers apply for short break funding; how centres allocate the funds as well as how support workers help carers identify outcomes; the conversations and tools which support that; and the reporting and evaluation that follows the short breaks.



4. Personal outcomes, short breaks and COVID-19

4.1 UNDERSTANDING PERSONAL OUTCOMES

There is growing commitment in Scotland across the health and social care system to focus on the outcomes important to children and adults using services and support, as well as their families and unpaid carers. Personal outcomes are like goals but tend to represent broader themes of wellbeing and quality of life. Identifying, capturing and working collaboratively towards personal outcomes involves building trust and relationships between people accessing support, their carers and practitioners. Outcomes for carers have been defined in the Talking Points framework (Cook and Miller, 2012).

Quality of life cared-for person	Quality of life for the carer	Managing the caring role	Process
• Quality of life for the cared-for person	• Maintaining health and well-being • A life of their own • Positive relationship with the person cared for • Freedom from financial hardship	• Choices in caring, including the limits of caring • Feeling informed/ skilled/equipped • Satisfaction in caring • Partnership with services	• Valued/respected and expertise recognised • Having a say in services • Flexible and responsive to changing needs • Positive relationship with practitioners • Accessible, available and free at the point of need

In our small scale study, a range of carers' personal outcomes were met through the TtL funded short breaks. The following section explores those outcomes and the carers' experiences of their short breaks.

4.2 OUTCOMES RELATED TO THE SHORT BREAKS

Carers used their TtL grants in various ways and the breaks were personalised to each individual's circumstances. There were contextual similarities to the breaks as a result of COVID-19, for example, most of the breaks were taken at home and involved adding something to the home environment, most commonly equipment to make it easier to spend time outside (Nina's greenhouse, Mark's garden bench, Anna's garden chairs, Margaret's shed, Frances's tent, Audrey's trampoline). Frequently, breaks supported a hobby or interest, for example, crafting (Isabelle, Megan), gardening (Mark, Nina), reading (Margaret), and manicures (Maria). Other short breaks involved leaving home to access breaks locally – yoga classes for Aleena and massage sessions for Rania. Only two breaks were more traditional overnight breaks taken away from home when restrictions eased later in 2021 (Anna, Lynn and Neil). Although the breaks were personalised to individual carers, the outcomes were commonly shared. Financial wellbeing, physical and mental wellbeing, improved relationships and a strengthened sense of identity were consistently identified by carers as being supported through their short breaks.

FINANCIAL WELLBEING

Carers felt that TtL grant funding enabled them to buy something they otherwise couldn't afford (Nina, Rania, Audrey, Mark), or save money on services they would have otherwise paid for (Maria). Carers appreciated that this money was specifically designated for a break from caring which gave them permission to prioritise themselves and not spend the money on other things (or other people):

> *The good thing about it is it's not my money. If it was, I would have spent it on the children or any other thing and not thought about myself – but this was given to me for that purpose. (Aleena)*

Importantly, the short break funding didn't feel like 'a handout' but something that made carers feel recognised and valued for their role:

> *I didn't feel we were sort of begging for anything or a freebie – the carers centre made it just sound, you know, you deserve it. (Anna)*

> *I felt it was some sort of recognition for the difficult job I'm doing for no pay. We work unpaid, we work for love. But make no mistake, it is hard work. It is my life, and it's a very difficult thing to do. (Mark)*

These examples demonstrate that receiving a financial contribution was not only a practical enabler for carers to take short breaks, but importantly, contributed to them feeling valued. It also emphasises the role of support workers in framing the financial aspect as an entitlement. These findings also link with known carer outcomes related to having 'freedom from financial hardship' and 'feeling valued and respected' (Cook and Miller, 2012).

HEALTH AND WELLBEING

Physical and mental wellbeing outcomes are closely connected in the carers' stories and in previous research (Thomas and colleagues, 2017). Some carers chose breaks to improve existing health conditions (Aleena), to relieve physical symptoms of stress (Rania), or to support their own need to shield (Isabelle). Short breaks supported physical wellbeing outcomes by enabling carers to spend time outside at home (Nina, Mark, Anna, Margaret, Frances, Audrey), take exercise (Aleena), and support basic needs like sleep (Lynn and Neil). However, breaks that contributed to physical outcomes also positively impacted mental and emotional health. Carers with a physical aspect to their breaks also reported reduced stress, improved mood, better sleep, feeling rested, more relaxed and able to cope.

Other carers chose to create extra space within the caring environment (e.g. the greenhouse, the shed, the bench, the tent) which created mental and emotional refuges. Nina described her greenhouse as a 'safety valve'; for Margaret, her shed is her 'cabin' where she can relax and enjoy 'me time'; for Frances, her tent is 'an absolute godsend', a place she can get breathing space.

Crucially, a key benefit of at-home breaks was remaining close to the cared-for person which alleviated feelings of guilt and anxiety at leaving them, a finding supported in other research (Tait and colleagues, 2017). By integrating breaks into the caring environment, carers could still 'be there' (Nina), 'within earshot' (Margaret) and be able to 'keep an eye' on the cared-for person (Mark, Frances). Short breaks away with the cared-for person had the same benefits for carers of not having to leave them:

> *I would not have relaxed going away and leaving my husband – that's the honest truth, I would not relax thinking of him being in here. I'd be on the phone all the time, and that's not relaxing, whereas he was there. (Anna)*

Time was also a factor that impacted emotional wellbeing. Carers reported the benefits of time saved by their short break. For Maria, not having to 'waste our whole day or our whole evening' getting a manicure was another benefit of having the nail equipment at home. For Anna, 'no rushing and no looking at the clock' was central to enjoying her break. Used to a routine revolving around hospital appointments, she chose a self-catering apartment over a hotel so she and her husband could be in control of their time:

> *Initially, I probably thought – well maybe a hotel because then I'll probably get spoiled more. However, we decided on an apartment… In a hotel it's us both up, both rushed,*

> *both showers, both need to be presentable sitting down in a restaurant for the food. In the apartment I could sit a wee bit longer with the pyjamas, to be quite honest. (Anna)*

This demonstrates the benefits of personalised breaks where the carer has choice and control. In Anna's case, she was able to choose what was more important to her – freedom from time restriction over perhaps being 'spoiled'.

"GETTING BACK TO A SENSE OF YOURSELF"

A common theme across the stories was the benefits carers gained from a strengthened sense of self through their short breaks. What helped make this possible were the holistic conversations with support workers, focused on personal interests to connect what carers enjoy with what could give them a break.

Again, outcomes were closely related. For instance, some of the breaks that involved spending time outside and supporting physical outcomes also enabled carers to pursue their hobbies and interests (gardening for Nina, vegetable growing for Mark, reading for Margaret). Positive mental wellbeing outcomes were also supported through hobbies / interests because they were grounded in what the carer enjoyed, for example, nail manicuring (Maria), gardening (Nina), knitting (Megan), reading (Margaret) and crafting (Isabelle). Having choice about the details, for example, being able to personalise equipment also let carers express their sense of self:

> *We've actually got a spare room in the house, and it's now my kind of office/dressing room – so that's where I've got my nail station. And I was able to pick which one I wanted... I was*

> *able to get something that looked quite nice as well in my room, just to make it part of my furniture in my room. I really like it, it's really pretty. And I changed the handles on the drawers to diamante knobs, because it's just more me, just more my personality. (Maria)*

Nina described her greenhouse as a place to 'rebuild' herself, to find balance, and a way 'to get back to a sense of yourself'. Maria also described the impact of her short break activity on learning new skills and her sense of self:

> *It gave me a bit of my own identity, something that I was good at. I'm not a very artistic person at all, and to be honest, I didn't think I was going to be that good at it – but it was still something that I enjoyed. (Maria)*

Maria's example links strengthened identity with building expertise which we see in other carers' stories. Gaining new skills created a sense of achievement for carers, particularly for more creative short break activities, for example, gardening (Nina) and crafting (Isabelle, Megan).

Carers felt that by purchasing equipment, their interests were given legitimacy (Nina, Maria). They described feeling more 'established' in their hobbies and that 'everyone knows it's what I do' (Maria, Nina), suggesting that signalling part of their identity to others is important.

Short breaks linked to interests also provided distraction (Maria, Isabelle, Megan); supported self-care and relaxation (Maria); and provided 'comfort' and a chance to 'recharge' (Megan). This suggests that breaks linked to hobbies strengthen identity and support emotional and mental wellbeing.

SOCIAL CONNECTION, RELATIONSHIPS AND OUTCOMES FOR THE CARED-FOR PERSON

Outcomes related to connecting with others had particular resonance in the stories, given the restrictions on social contact due to the pandemic. The short breaks described here helped support social connection in different ways – between strangers, peers, couples and families. For a couple in a remote area, a bench bought with a TtL grant meant they could spend more time in their garden which increased their social interaction with passers-by and relieved isolation (Mark).

> *There are holiday makers going by, hikers and cyclists. And it just gave us the opportunity to be out in the garden and meeting people passing by. Even if we could only speak to them at a distance. It was social contact at a time when we were getting very little. (Mark)*

Social connection with peers was supported through group exercise classes (Aleena), families spending time together in their gardens (Audrey, Frances) or sharing self-care activities (Maria). For Nina, she was able to source a greenhouse from a friend and fellow carer which meant the greenhouse had special significance:

> *I told my friend, 'Now, I feel it's 'our' greenhouse – we've got a physical connection linking us across the miles'. When I'm in the greenhouse, I think of my friend having worked in it previously, and we swap plants and seeds and things. (Nina)*

For parent carers, it was an opportunity for them to refocus on their relationship as a couple outside their caring roles:

> *It was really nice for us to have time just the two of us, just so that you're strong as a unit… it was just nice to go away and do things just the two of us. (Lynn)*

Breaks benefitted caring relationships and supported outcomes for the cared-for person directly if they participated in the short break (Anna, Maria, Mark, Audrey) or indirectly through the carer being more relaxed, patient and able to cope (Lynn and Neil, Isabelle, Nina, Rania).

The short breaks' contribution to the wellbeing of cared-for people is a common theme across the carer stories. We know that outcomes for carers and the cared-for person are closely related – 'quality of life for the cared-for person' is a carer outcome in the Talking Points framework (Cook and Miller, 2012). In some cases, it seemed the cared-for person's outcomes were a deciding factor in the type of break identified, for example, those chosen to help support the cared-for person's recuperation (Anna) or disability (Audrey). Carers also emphasised their appreciation for nurturing the caring relationship through their short break:

> *One of the bits of the garden I do is a patch outside mum's window. She's in her room all day long. I keep changing what's there so it's always interesting and there's always something flowering. It feels good that I am able to make that contribution within my caring role, creating something nice for her to look at it. (Nina)*

> *Claire was very, very taken with [the bench]... I think it helped her tremendously. You can imagine how difficult it is for her and it gave her great enjoyment. I know that, that's a fact. (Mark)*

For Mark, the short break (as part of a wider support package) helped improve his morale and reframe his perspective on the relationship with his wife:

> *I see it now as this is a precious time for us together. We're in this together, it's what I need to do, what I want to do. I just wasn't equipped to do it and now I'm in better shape.*

Positive reframing of the caring relationship enabled by breaks was also evidenced by previous research (Roberts and Struckmeyer, 2018). Studies also attest to the importance of a positive relationship with the cared-for person in helping carers continue in their caring role (Victor, 2009; Shared Care Scotland, 2012; The Older People's Commissioner for Wales, 2018) which is explored in the next section.

4.3 SUSTAINABILITY

The theme of sustainability surfaced in two key places in the data – continuing in the caring role; and lasting benefits of the short break.

CONTINUING IN THE CARING ROLE

In terms of sustainability, perhaps most importantly, short breaks enabled carers to keep going in their caring role during an incredibly stressful time. Breaks that supported health and wellbeing outcomes also increased physical, emotional and mental capacity, without which carers felt they wouldn't have been able to continue in their caring role:

> *I basically coped on my own through the lockdown, it was very, very difficult and I came to the point of having a virtual mental breakdown. (Mark)*

> *I think if we hadn't had a break at that point, we'd have had a breakdown. (Lynn and Neil)*

The language used by carers to describe the impact of breaks and support from centres – 'a safety valve', 'a lifeline', 'a godsend', highlights how crucial breaks are in sustaining the caring role. It might also suggest that some carers are approaching desperation before getting a break. This is evident in previous research by Shared Care Scotland (2012) which found that carers felt short breaks were a form of early intervention to prevent the breakdown of the caring relationship, but also that it often came too late. It was not unusual for the carers in this study to have gone years without a funded short break. Three of them (Nina, Mark and Aleena) were taking a TtL short break for the first time. Only one carer (Maria) was taking regular short breaks which she started accessing about four years ago. This suggests barriers to short breaks highlighted from previous research (Shared Care Scotland, 2012) may still persist and more needs to be done to enable carers access to regular, personalised breaks from the caring role.

As highlighted in the previous section, breaks also supported positive caring relationships which helped carers sustain their caring role.

LASTING BENEFITS

A feature of the support process during the pandemic was to encourage carers to focus on activities with lasting benefits over quick fixes. Carers responded positively to this and most opted to use their short break funding for activities over a longer period of time (massage vouchers, yoga classes) or equipment with long-term use:

> *For me, [the greenhouse] is a better break than a night or two away, because it's something permanent that just keeps giving. It's not just a lovely memory. (Nina)*

The stories demonstrate how breaks sustained benefits over a longer time period, for example, creating something to keep (Isabelle's diamond paintings, Megan's knitting) and long-term use of equipment (the greenhouse, garden chairs, nail equipment, bench, tent, trampoline). Where short break activities involved learning new skills, some carers talked about their interests expanding into other areas as their expertise improved. Nina's greenhouse helped encourage her to purchase a polytunnel and explore being more self-sufficient with food. For Maria, getting the nail equipment 'was just something to do and a bit of a project', but as her skills improved her interest increased:

> *I thought, you know, what else can I do with this, can I maybe start doing acrylic nails or, you know, like different types of nails? (Maria)*

These examples demonstrate the longer-term benefits that can come from short breaks which originate from personal interests and how new learning can lead to other activities. This indicates that perhaps alternative forms of short breaks focused on the home environment add another dimension to the sustainability of the caring role, due to being focused on weaving relief and respite into everyday life as opposed to providing a temporary relief. For example, Brimblecomb and colleagues (2018) argue that traditional short breaks away may only be sufficient to provide temporary relief rather than any substantial improvements before returning to an often very demanding caring situation.

However, carers who chose the more traditional short breaks away also described lasting benefits in terms of the novelty of the experience and the physical and spatial break which allowed them to recharge:

> *Looking forward to it was a biggie. I think everybody's the same – it's nice to pack a case, isn't it? I love the whole kind of getting ready and thinking you're doing something different and getting away from your usual stuff. It gave us something to look forward to. (Anna)*
>
> *We weren't expecting amazing results from two days but it did have a big impact. Surprisingly more beneficial than I thought it would be… I would say it's gradual dissipation but it's still definitely longevity. I still feel the benefits now… (Neil)*

Interestingly, carers reflected on a sense of anticipation before a break which amplified their overall enjoyment and longer-term satisfaction with the break. Anticipation was also part of the enjoyment for carers accessing regular short breaks over a longer period of time, for example, Rania's massage vouchers and Aleena's yoga classes. Both carers described how much they looked forward to their activities.

However, where carers are spreading their short breaks over longer periods of time to create lasting benefits, circumstances can change. For Aleena, she had to suspend her yoga classes when her mother-in-law's condition worsened, which highlights the need to monitor the suitability of short breaks over time.

4.4 OUTCOMES RELATED TO THE SUPPORT PROCESS

It is crucial to recognise that many of the outcomes discussed above are part of an overall process of support. The relationships between carers and carer centres are underpinned by trust and in themselves constitute an important element of the short break and its impact on carers' lives. The Talking Points framework (Cook and Miller, 2012) identifies a number of 'process outcomes' which 'relate to the experience that individuals have seeking, obtaining and using services and supports and can have a significant influence on the extent to which other outcomes are achieved' (p11). Previous research shows that outcome-focused conversations are an effective intervention in their own right (Miller and Barrie, 2016), reinforcing the importance of considering the processes and systems through which carers navigate alongside measuring the output (e.g. a short break). Process outcomes include:

- Feeling valued / respected and expertise recognised
- Having a say in services
- Flexible and responsive to changing needs
- Positive relationship with practitioners
- Accessible, available, and free at the point of need

In our interviews with carers, we identified three main outcomes related to the support process that contributed to personal outcomes: increased access to support, reduced isolation, and reduced administrative burden.

INCREASED ACCESS TO SUPPORT

Carers found initial contact with centres to be a positive experience. Although some described uncertainty about what help might be available from carers centres (Nina, Mark, Margaret), carers described finding a 'lifeline' (Margaret) and a 'gateway' to a wide range of support (Mark). Centres provided access to a network of other agencies, saving carers the time and effort of searching out individual organisations:

> *So much help out there, practical help. We've had help with insulation in the house, we've had help upgrading the heating in the house and things like that. [The centre manager] is brilliant, her organisation puts you in touch with everyone who can help you. (Mark)*

Whether or not carers approach centres to enquire about short breaks, workers are attuned to identify other needs and to connect carers into a wider network of support:

> *After my call to the carer's centre, they've now offered me some counselling. They clocked when I'd phoned and asked about the break that there was a need, even just that communication with the carer centre, has led on [to other things]. (Lynn)*

Carers centres provide support that goes beyond the immediate caring role and considers the 'whole person,' their circumstances and needs. This is a crucial element of how carers engage with centres and contributes to their sense of feeling less alone and isolated.

REDUCED ISOLATION

COVID-19 meant significant curbs on social contact. Carers were isolated for different reasons and assumptions about isolation being a rural and remote issue were challenged. Some carers in urban areas, used to visiting carers centres in person, felt very isolated at home, while

some carers in rural and remote areas didn't because they had the technology and skills to access support and social connection online:

> *I don't actually feel cut off anymore, because I know that if I wanted to talk to one of my friends, I could just WhatsApp or have a Zoom and do that. (Nina, rural area).*

Support from centre workers helped carers feel less isolated and not 'cut off' particularly through lockdown. Regular contact was highly valued and made carers feel cared for:

> *I do feel that with them being there I can call any time and they have been a great boost and helped me tremendously…And all through COVID they kept in touch, phoned us up to find out how things were and then we'd find them at the door with masks on handing over lovely wee packs like afternoon teas… it was just a lovely feeling to know that somebody was caring. (Margaret)*

REDUCED ADMINISTRATIVE BURDEN

Relating to the short breaks specifically, carer centres provide support with the application process. As a result, the carers consistently described this support and the process itself as 'straightforward', 'quick', 'simple' and 'easy' with options for the workers to complete paperwork and make bookings. Some carers reflected on the natural feel of the application process, that it consisted of 'a conversation' and 'just talking'. We already know from previous research that carers experience complex, time-consuming processes to access support including short breaks (Shared Care Scotland, 2012; Feeley Review, 2021), so reducing administrative burden cannot be underestimated as a form of support.

Overall, the support process made vital contributions to carers, making support accessible, responsive and saving time and effort. Relationships with support workers were positive and carers felt valued. Essentially, processes made access to a range of support, including short breaks, easier for carers.

The following section considers in more depth the operational and structural processes that underpin TtL funding. This will help us understand how carer centres negotiate between supply and demand of short break funding, the tools they use to ensure that carers access the best break for them, and how they report and evaluate these processes and activities.

5. Understanding carer centres' processes – managing and promoting the TtL grant

Alongside the carer interviews, we spoke to six carers centres across Scotland to understand how they manage and distribute TtL . We asked them to reflect on their processes, tools, conversations with carers and ways of recording and reporting impact. Below is an exploration of these key areas.

5.1 MANAGING THE TIME TO LIVE GRANT

During COVID-19, TtL criteria was relaxed to include parent carers. Though parents could access the Scottish Government funded Take a Break Scotland scheme, managers appreciated being able to offer TtL grants during a particularly challenging time for this group:

> *I've always felt personally, a bit guilty when we're delivering our Time to Live fund. Oh, you're a parent carer, you can't have it. When they were allowed, we actually targeted them. We gave them priority because they were a group that we had never been able to fund previously. (Centre 4)*

The total value of the TtL grant has remained consistent over the years (approximately £500k). Different amounts of funding across centre areas (both TtL and match funding) have led to varying approaches to managing and promoting the fund. Some carers centres accept direct applications from carers, while others strictly oversee applications to the fund due to a scarcity of funding. Some centres also try to create an 'equal playing field for everyone' by designating the same amount of TtL funding to each carer (Centre 4).

Due to different area characteristics, carers centres experience differing degrees of tension between the demand versus the supply of short break funding.

5.2 PROMOTION, ACCESS AND REACH

The funding from Shared Care Scotland and the demand from carers in the catchment area impacts how carers can access the funds. Some centres actively promote the grant on their website, social media and newsletters, but there was a sense of caution about promotion to avoid being overwhelmed:

> *We've got a centre-wide website which promotes short breaks and there is a mention of Time to Live within that. We don't actively promote beyond that, we're busy enough without further promotion. (Centre 3)*

Centres also reflect on the importance of increasing promotion during times when carers are most busy or worn out, for example, after Christmas. Some carers centres however are concerned about promotion due to limited funds and some choose not to actively promote the fund at all because of this. In this way, they can manage demand and mitigate the risk of applications being unsuccessful:

> *From an organisational perspective, [actively promoting] adds pressure because we're inundated with enquiries, we're inundated with people wanting this money and having adult carer support plan conversations. So, we're trying to have a balance so, what's too much information and what's just enough. (Centre 6)*

For centres, this balancing involves constant brokering between the demand from carers and access to different pots of funding alongside the TtL grant. Similarly, centres manage demand through different approaches to offering repeat short breaks. Some carers centres offer their members repeat breaks every year and actively remind carers, while others concentrate their efforts on identifying new carers for the breaks.

More recently, the move to digital and remote working as a result of the COVID-19 pandemic has often meant that carers can only access and apply to carers centres' short break funds through digital means – online, via email. This has led some centres to consider whether they are reaching those carers with limited digital capabilities.

DIGITAL EXCLUSION

Centre workers and carers identified digital exclusion as a challenge exacerbated by the pandemic, including lack of access to equipment and/or digital literacy. One centre conducted a survey which told them that many of the carers in their areas could not access their online forms and thus could not apply for any short break funding. One carer described the impact of digital exclusion on their ability to access support:

> *I used to have my Carer's ard, but that's all done on computer now and I don't know how to use a computer, so I'm missing my Carer's card very much so. It gets me into the gym, the swimming, libraries – but because I've not got the Carer's card, I can't get into the swimming. I'm quite obese and I loved going swimming and going to the gym, but I cannae do that anymore. (Isabelle)*

Some centres were able to address some exclusions by accessing funding for equipment, internet access and skills training:

> *We managed to work with one of our partners working around digital poverty and digital inclusion. We got that carer a laptop, free of charge. We were able to get them a mobile phone with data so that they could get online. We worked with them on digital awareness and online security. That carer has transformed their lives basically, they have been doing online engagement, they have been attending training courses, it has really opened up a whole new world for them. (Centre 6)*

This shows that centres are constantly adapting to the needs of the carers in their community and they are taking proactive steps to counter some of the digital access barriers. Some centres however, reflected on the challenges of cultural and language barriers.

CULTURAL AND LANGUAGE BARRIERS

Carers centres described difficulties in reaching some carers in their communities due to varying cultural perspectives on the caring role:

> *[Some BAME carers] don't see it as a caring role as such, it's more like 'I have to do it because it's my duty, it's my responsibility'. (BAME support worker)*

> *We always find the Chinese communities hard to reach because they are very self-sufficient and don't recognise the word 'carer' in some regards. (Centre 6)*

Some centres have dedicated BAME support workers to help address language and information barriers, although this can lead to an overreliance on carers centres:

> *There is trouble with accessing information in their language so the information is there, but they don't understand how to make use of it. So what has happened really is that they've kind of come to rely on us as their source of information. So they'll call and ask for advice and information about just about anything under the sun. (BAME support worker)*

To facilitate access to harder to reach groups, one centre described holding information sessions with local partners and community organisations, including GP practices, social work teams, the third sector interface and food banks to raise awareness of the centre's support.

Difficulties also exist in rural and remote areas where some conditions, specifically alcoholism, might be stigmatised due to local cultural perspectives (as opposed to urban areas):

> *We live in a small community… traditionally islanders are private people… I don't know if it's a stigma, an embarrassment. They just play it down. Although for the carer, it would be a horrendous situation to be in but they don't come. (Centre 4)*

Conditions like alcoholism seem to carry more stigma and shame in rural communities, which could deter carers of people affected by this to identify as carers and seek support.

Overall, our interviews indicate that carers centres are aware of these various challenges to reaching carers and they are continuously attempting to mitigate them.

5.3 THE SUPPORT PROCESS

The support process provided by centre workers starts with an application for funding which involves identifying the right break and brokering to build a support package around the break. The support process is integral to creating the conditions for personalised short breaks by taking the administrative burden off carers, helping them identify their outcomes and draw on their interests to rethink short breaks.

APPLICATION AND BROKERING

Carers usually access the TtL grant through their local carer centre. Some centres allow carers to apply directly, most frequently via email using a form. This puts the onus on the carer to take initiative and articulate their needs. Some carers, however, are excluded by the digital process which has led some centres to identify new ways to promote the short break funds through direct mail or word of mouth. Other centres do not have a direct application process but will apply on behalf of a carer following a conversation about what's important to the carer, or their personal outcomes. This method allows the carer to bypass filling in the form themselves which is especially useful if they have limited digital access or might struggle to articulate what short break they are looking for.

Carers centres often engage in brokering where they mediate the process of carers accessing short break funding to make it as 'straightforward and as simple and as accessible as possible for the carer', to ensure any eligibility criteria are met and 'to monitor' the budget. For example, one centre reflects on the development of a new form:

> *We've devised a form that actually asks them; are you looking for a break away in Scotland? Are you looking for a day out in Scotland? Are you looking for a break anywhere else in the UK? Are you just looking for an activity or a hobby? So, that we can send that back and then staff can look and think, well it's maybe the Scot Spirit application that needs filled in, or it's the Time to Live or it might need both. (Centre 1).*

This further emphasises the person-centred focus workers take to determining the best short break for each individual. Applications are not predetermined by the specific fund, but focused on identifying carer's needs more broadly.

Some workers felt that collaborating with carers on the application form gives the process more rigour as an in-depth conversation supports a deeper understanding of a carer's outcomes and how these could be met:

> *Some centres will take an application directly from the carer and then that's it…how do they possibly know that is going to help that carer achieve an outcome? Because you're relying on what the carer is telling you… (Centre 6)*

A conversation-based approach undoubtedly takes more time for support workers and, therefore, has resource implications. Also, conversations with carers about personal outcomes are not without challenges which are explored further in this section.

DECISION-MAKING AND ALLOCATION

Some carers centres use a panel to make decisions on grant applications. This usually means any applications for short breaks are approved by their board of directors in a panel discussion, some of whom are current or former carers. Managers feel this is a way for board members to stay connected with the centre membership (Centre 2).

The process of allocating short break funding can be complex and emotional at times as workers reflect on the lives of some in a caring role, particularly for young carers: ‘Oh my God, I can’t believe that a five-year old’s doing this’. Involving carers in panels and decision-making provides vital insight into the realities of the role:

> *It really helps in that process to have a panel that consists of not just staff but carers themselves who have got hands-on experience of the needs for breaks and access to these funds. (Centre 6)*

Support workers are also routinely involved in panels. Managers valued the depth of knowledge workers had about carers and ‘who’s in real need’ (Centre 4).

> *The advantage we have is there’s a good chance that our staff have been to visit carers. So, whilst we in the office wouldn’t know the personal circumstances or know the people, the staff do. (Centre 4)*

PARTNERSHIP WORKING

The challenges posed by COVID-19 in terms of accessing traditional short breaks revealed the importance of partnership working and trust between Shared Care Scotland as the funder and carers centres as delivery partners. Managers highly valued the freedom to design applications and distribute funding to meet the needs of their local area:

> *We can make the decisions locally, we know our carers, we know who’s in need. And we know where that can be best put to good use. And whether that’s improving health and wellbeing, helping them to stay in their caring role, or helping them to find something outside their caring role, we have that intelligence that we can make it work. (Centre 5)*

Centres also valued the support that Shared Care Scotland provided and the space to be creative in their approaches to managing funds and finding innovative solutions:

> *I think as an organisation, we've learned so much but we've had the permission to learn and grow from funds like Shared Care Scotland and the Time to Live that we've been trusted to make really good decisions about the way that we offer that service. From the moment we went into lockdown it felt flexible and supportive. (Centre 1)*

Trust and permission were crucial to centres to be able to not just respond to COVID-19 but to learn. This was also supported by collaborating with other partner organisations to share ideas and updates:

> *That was the beauty of having the connections that we've got with the other centre managers. The other three centre managers and our carers' lead, we would come together and we would have regular COVID updates. And ideas would come maybe from our centre or other centres. The same also with the other centre managers across Scotland, there were regular updates. (Centre 5)*

Shared Care Scotland provided a valuable facilitative role between delivery partners using Microsoft Teams to support collaboration, sharing ideas, best practice and feedback.

Centres also worked with local community groups and consortiums, food banks and Third Sector Interfaces to identify hard-to-reach and isolated carers (Centre 6).

5.4 FRAMING THE CONVERSATION

IDENTITY AND OUTCOMES

Support workers seek to have conversations with carers that explore their personal outcomes and interests to help choose the right break. Workers described wanting to help carers 'feel seen and heard in their own right' (Centre 6). We know from previous research that caring can be all-consuming and can alter how carers perceive their identity (Shared Care Scotland, 2012), which was also evident in this study:

> *We don't think about ourselves when we're in a caring role – we just think that person needs this, that, the other, you run about and you forget, you forget yourself. (Rania)*

For some carers, a conversation focused entirely on them is a novelty, as one support worker highlighted:

> *I had a chat with a carer who said, "I've been taking my husband to the GP for years. Sitting there with him, not once has the doctor asked me how I'm feeling. It's like I'm invisible. (Centre 4)*

If they do identify as carers, workers described how they might still de-prioritise themselves over other carers they imagine to be more deserving or worse off (Centre 5, Centre 4):

> *Some people don't think they deserve a break, and they think if they take it, it means somebody else won't get it. (Centre 1)*

Some carers were uncomfortable with accessing funding for breaks. For some, this was to do with awareness of their 'privilege' compared to other carers (Maria, Lynn and Neil). One described feeling 'like a fraud' for applying for a short break (Maria); another was concerned about appearing 'greedy' for reapplying (Frances). This echoes similar feelings of guilt reported in previous research (Victor 2009; Shared Care Scotland, 2012).

These examples suggest that some carers find it difficult to shift their focus on to themselves and support workers might need to persist to overcome carers' tendencies to put others first.

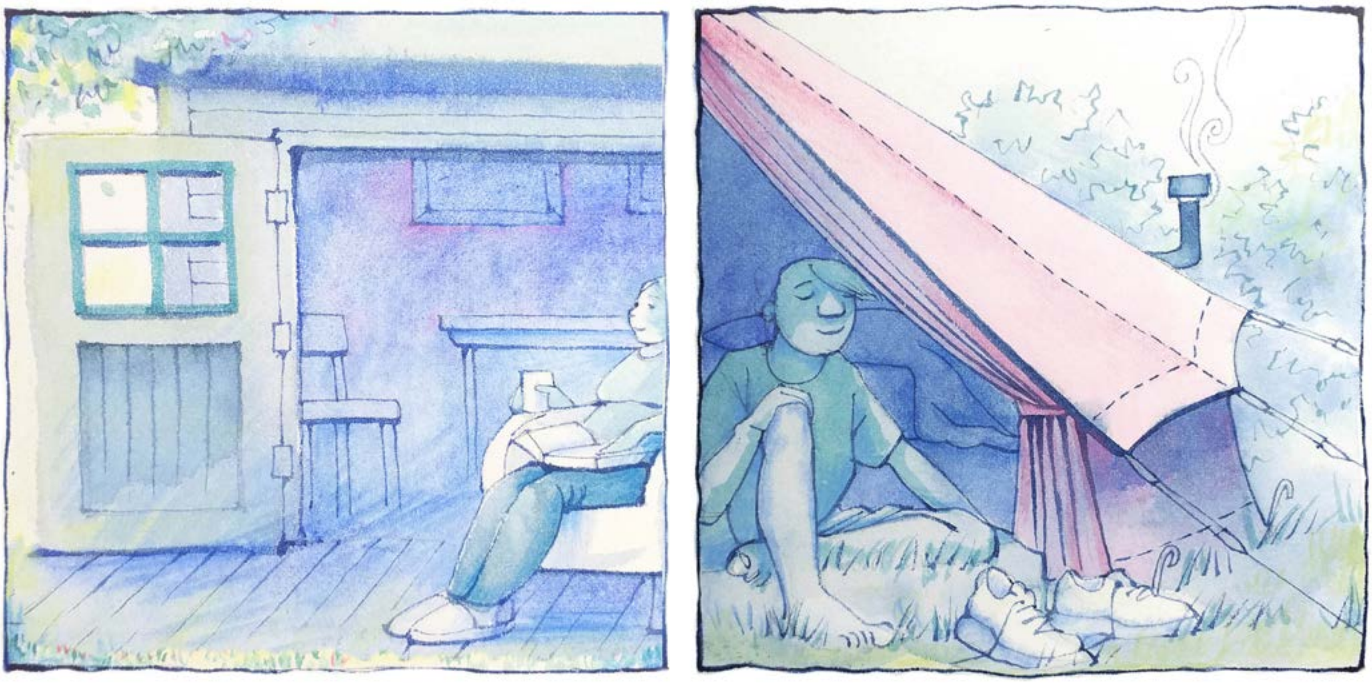
A further challenge to shifting the focus to outcomes might arise when carers are more used to conversations about assessment and eligibility. One manager reflected that some carers found outcomes-focused conversations just 'rigmarole' and delayed access to money they felt 'owed' (Centre 6). This attitude jarred with carers centres who saw themselves as fundamentally outcomes-focused organisations, unlike other agencies perceived to prioritise cost-saving:

> *[Statutory social services] are very focused on the money aspect and it's unfortunate that we're having to say this in this day and age but social work, health and social care partnerships are always money-driven in terms of how much money they can save rather than how they can meet the needs of the individual… (Centre 6)*

Establishing trust between support workers and carers was at the centre of the support process and of outcome-focused conversations. Workers were mindful of the importance of listening and that establishing trust was a prerequisite 'before you can start to have the more difficult conversations' (Centre 6).

What enabled trust between workers and carers was when they came to the centre on the recommendation of another carer. Workers noticed that in these cases, a level of trust already existed, built on trust between peers:

> *If the carer says, 'Oh, I was just talking to Jean and she was telling me all about you'…. those conversations we can't get them to stop talking, they just tell you everything. Because they've already got the trust because Jean's told them that we're amazing. (Centre 6)*



Workers acknowledged that trust was more difficult to establish when engaging with carers online rather than face to face. Although some centres still did ‘doorstep visits’ to more vulnerable carers, most conversations were taking place remotely, and building rapport took longer.

Also, centres highlighted instances of carer distrust carried over from experiences with statutory services:

> *…if social work have made a referral into this organisation; there’s a level of distrust at the beginning… (Centre 6).*

This suggests initial barriers that workers might need to overcome to begin to build trust with carers and indicates cultural differences between third sector and statutory carer support.

RETHINKING SHORT BREAKS

Conversations with carers had to shift considerably to respond to the COVID-19 pandemic and to support them to rethink short breaks. Before COVID-19, some carers had used a TtL grant for a traditional short break away to a hotel, spa or self-catering accommodation. Regardless of previous experience, expectations of short breaks had to be re-examined. Sustainable benefits were critical with more limited options, so carers were encouraged to consider ‘long-term benefit, not a short fix’ (Centre 4).

> *During COVID it became a bit more challenging because obviously the hospitality industry was affected, and if people had previously chosen to get massages or go to the theatre you know, all that sort of stuff had gone. But we didn't struggle to identify a break, the carers still came up with ideas but it was just maybe more creative. (Centre 3)*

Centres had to challenge existing notions of short breaks and reframe them as something that could be taken within the caring environment. One centre asked carers to think about what 'a pocket of respite' might be for them (Centre 6). Creative breaks related to the carer's interests, assets and hobbies were also encouraged, to support a sense of identity outside the caring role. Carers centres reflected on the gains of rethinking breaks:

> *We now have a more creative list of short breaks that we'll take forward. So, we've had these more creative conversations, as a team, we have become more creative, carers became more creative and we will be able to take that forward. (Centre 3)*

Breaks were identified through the outcomes conversation, where workers 'planted seeds/ideas' (Centre 4), supporting carers to think beyond what they wanted to determine what they might need:

> *The carer knew she needed something – she even had a fair idea of what she wanted – but maybe that's not what she actually needed. She needed to get out of her isolation and actually go someplace to do an activity. It was a process of telling them how to reach that goal really.*

The freedom to choose a break that was right for them resulted in outcomes for carers being met in unexpected ways, as this observation from a centre manager reflects:

One carer put in a receipt for an air fryer. I thought, 'Oh my goodness, that's not covered by the fund'. But then I actually stopped to think, well actually, it's healthy eating. That's good for your health and wellbeing and it saves time. I phoned her for feedback and she said, 'I have one pot to cook with now, not lots. So, it saves me on the washing up'. And she got so much pleasure out of it. It wasn't just something for cooking because she didn't get out; she was tied to the house. She had a new topic of conversation, the carers were in to see what she was cooking with, and suddenly, it was almost like she became the centre of attention rather than the husband. (Centre 4)

This example underlines the importance for centres of trusting carers to know what they need and to support their personal choices. It also reinforces the value of the conversation with a carer before decisions are made – to understand what's important to the carer and the meaning they attach to what they have applied for.

TOOLS

Carers centres have varying experiences of using tools and frameworks for conversation with carers. Workers described different approaches to opening the outcomes conversation. Some asked ‘what’s important to you?’, others led with ‘there’s this fund you can access’. Some of the centres used tools to guide the conversation, including the Adult Carer Support Plan, Adult Carers Framework tool, Inspiring Breaks Toolkit and a bespoke carers’ portal. Tools didn’t appear to dictate the conversation or make it prescriptive. This is backed up by carers who reported positively about conversations irrespective of whether tools were used or not. Workers reflected that skills become so embedded and part of the organisational culture ‘you might not even know it as a toolkit, it might just be the way you work or the way you speak’ (Centre 6). Centres also described a culture where all staff support carers to access breaks, from the person on the reception desk to the Chief Executive:

> *It’s everybody’s job to do Time to Live, everybody. We all have that mindset of, ‘What does this carer need and what would benefit them?’ So it is everybody’s job to do it. And that makes a big difference because it’s not just a couple of people in the organisation talking about breaks and Time to Live, it’s everybody. (Centre 1)*

Workers described conversations as holistic, ongoing, ‘never finished’, and weaving through a range of areas including anticipatory and emergency planning, benefits and entitlements under the Carers (Scotland) Act 2016. Emphasising entitlements was important as it gives carers ‘permission’ to take breaks from their caring role and consider their own needs.

A holistic approach to conversations also helps mitigate the risk of carers not getting the right break. One centre highlighted instances of carers coming back early from a break:

> *They’ve been too worried about the person that they’ve left behind. But then it’s maybe because it’s the first time they’ve ever done it and so there’s like guilt, alongside trying to relax but not being able to’ (Centre 3).*

This highlights the importance of the support process before the break and exploring with the carer any concerns or worries they might have ahead of time. Recording outcomes, reporting, and evaluation processes also support centres to reflect on learning from carers’ experiences of short breaks.

5.5 RECORDING, REPORTING AND EVALUATION

A vital part of the support process carers centres provide is to understand the impact of short breaks by recording carers' personal outcomes. This serves a human and an administrative function. Workers recognise the value of the carer's story and that recording goes beyond form-filling:

> *One of the positives that I find with our service is carers tell us the story. They don't need to keep telling us because we document everything and we build the Adult Carer Support Plan based on those conversations so that they don't need to keep telling their story over and over again. We hold it for them. (Centre 6)*

Carers centres usually report on the TtL grant using case studies and they gather feedback from carers through evaluation forms and focus groups (e.g. Centre 5, Centre 6). Their reporting often conveys the qualitative difference short breaks have made to someone's life, including personal accounts, video diaries, and photos. Due to unforeseen circumstances, the short breaks might not always go according to plan, especially considering COVID-19 or other challenges. Centres note the importance of learning from these cases:

> *We've had a few that have gone wrong and that people haven't got what they needed out of it. So, again it's good for us to know when things haven't gone right. (Centre 2)*

Managers feel that reporting is supported by the TtL principles (see appendix 2), which helps structure their reports and align with their organisational vision, values, local policies and procedures. Some centres also seek extra rigour for their evaluation processes in the form of external assessors (Centre 5).

6. Key learning points

This study explored how carers and delivery partners experienced TtL short breaks through the pandemic. The aim of our research was to address knowledge gaps identified in a recent scoping review (Seddon and Prendergast, 2019) about the impact of alternative short breaks on carers' personal outcomes.

This section highlights key findings against the research questions on page eight in relation to carers' experiences of short breaks, personal outcomes and the organisational processes that underpin the delivery of the TtL grant. These summary points provide insights to inform development and improvement activities relating to the TtL grant and, more widely, to a personal outcomes approach for working with carers.

CARERS RESEARCH QUESTIONS

Impact: How has the TtL grant supported carers to meet their personal outcomes?

We learned that breaks are personalised to individual carers but outcomes across the carers are commonly shared and included:

- Health and wellbeing
- Financial wellbeing
- Improved relationships
- Reduced social isolation
- Strengthened sense of self

Personalised short breaks happen when carers are enabled to assign their own meaning to what they use funding for. Choice and control of what matters to them and their priorities is fundamental to supporting personal outcomes.

Carers reflected on multiple, inter-related personal outcomes which are being achieved with little 'investment' / funding. Physical, mental and emotional outcomes are closely related and improvement in one area helps support improvement in others.

The unique characteristics of the breaks had specific impacts on people's experiences:

- Breaks which add something to the home environment created extra physical space but also emotional and mental refuges.
- Breaks linked to hobbies and interests are an effective way to support carers to rediscover and strengthen their sense of self.

Sustainability: How are TtL grants supporting carers to achieve a more sustainable balance between caring and other things they want in their lives?

A feature of the support process provided by carers centres during the pandemic was to encourage carers to focus on activities with lasting benefits. Most carers chose to spread the funding on activities which happened over a longer period of time or on equipment with long-term use. Only two chose the more traditional short breaks away from home. However, breaks taken over time need to be reassessed for suitability if circumstances change.

The longer-term use of how people chose to spend their funding had several key impacts on the sustainability of the caring role but also on people's outcomes:

- Short breaks which relate to carers' hobbies support new learning, a sense of achievement and can lead to further interests, creating long-term benefits. It could be argued that 'pockets of respite' embedded in the home environment that can be accessed regularly provide longer-term benefits compared with more traditional short breaks away.
- Short breaks supported carers to continue in their caring role. Several described reaching crisis before accessing a break, a finding echoed in previous research. It was not unusual for the carers in this study to have gone years without a funded short break, suggesting known barriers to access still persist. This further supports the recommendation in the Feeley Review (2021) that carers should be given a 'right to respite'.

Process: How did carers experience the process of accessing the TtL grant?

The support process provided by centre workers improved carers' outcomes related to accessing a wide range of support, reducing social isolation and reducing the carers' administrative burden, echoing previous findings (Cook and Miller, 2012).

Overall, the process made access to a range of support, including short breaks, easy, straightforward and quick. Outcome-focused conversations were supportive and helped foster trust and positive relationships between carers and workers. Conversations were an intervention in themselves. Carers appreciated the opportunity to reprioritise themselves through these conversations as the funding was specifically designated for their short break which helped them not spend it on other things or other people.

CARERS CENTRES RESEARCH QUESTIONS

Promotion: How do carers centres currently promote TtL? Are there particular groups of carers that they feel they are not reaching?

Carers centres often do not promote the grant to avoid being overwhelmed by applications. Some centres allow carers to apply directly while others choose to apply with and on behalf of the carer.

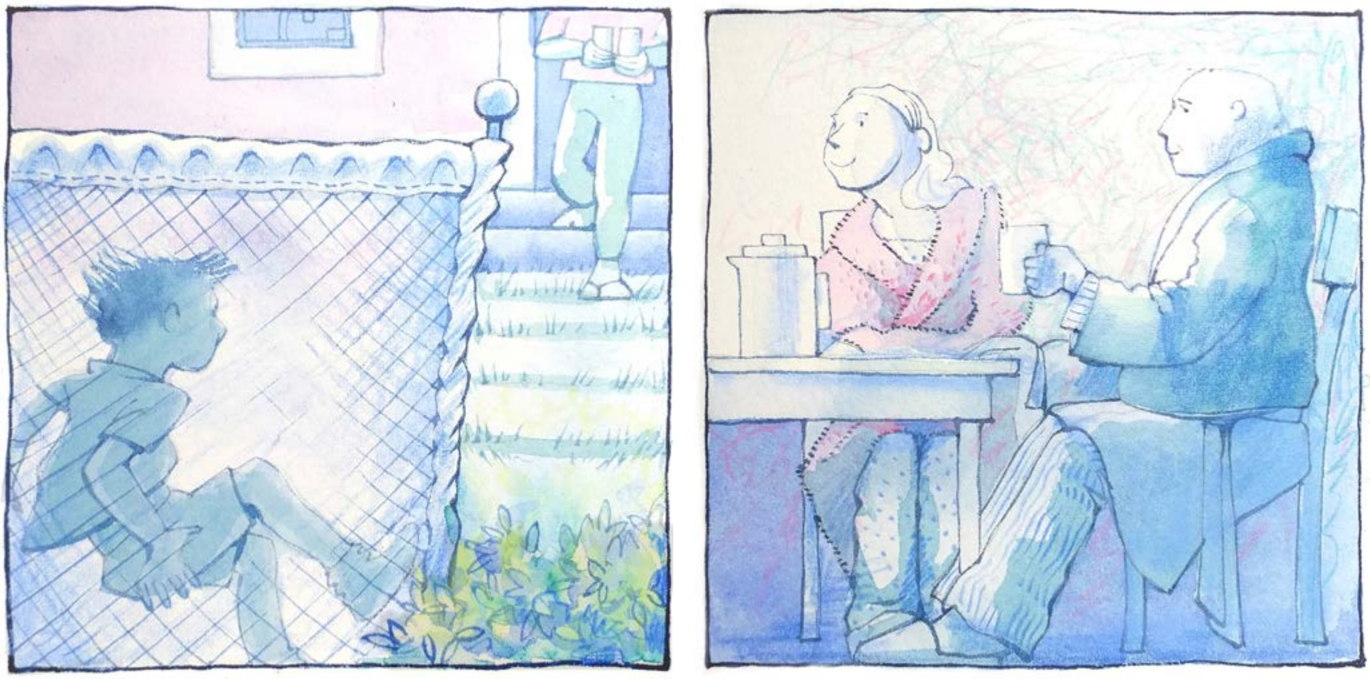
Centres and carers equally highlighted that the move to digital working due to COVID-19 can lead to the exclusion of some carers who do not have digital access or capabilities. Carer centres also highlighted that due to differing cultural perspectives and attitudes towards what constitutes caring, some people might not identify as carers which means they might be excluded from support services.

Identifying outcomes: How do centres work with carers to identify what's important to them / their personal outcomes?

Personal outcomes are identified through conversations between support workers and carers. Outcome-focused conversations help clarify what matters to the carers and why. Tools can support conversations but aren't essential to the quality of the conversation. Listening and building trust are key skills that support workers use to have positive relationships with carers.

Shifting the conversation to focus on outcomes has challenges, particularly when carers are used to conversations with statutory services about eligibility and assessment. Some carers find it difficult to shift their focus to themselves and support workers might need to persist to overcome a carer's tendency to put others first.

Conversations with carers had to shift considerably to respond to the COVID-19 pandemic and to support them to rethink short breaks. Notably, carers centres encouraged carers to focus on breaks with sustainable, longer-term benefits over 'quick fixes'. However, when breaks are taken over longer periods of time, caring situations can change and breaks may become unsuitable, which support workers need to monitor.



Support workers helped carers think about what ‘pockets of respite’ could be accessed from home. Carers’ hobbies and interests were used as inspiration for short breaks and a way to reconnect carers with a sense of themselves. This resulted in more creative short break options which could be shared across a network of delivery partners.

Delivery partners noted new learning and an increase in creativity around short break thinking as a result of the pandemic. This relates to the call in the Feeley Review (2021) for more ‘imaginative options’ for respite and breaks.

The support process helps create the conditions for personalised short breaks by making access to funding straightforward and helping identify personal outcomes, building on carers’ interests.

Recording and reporting outcomes: How do centres capture whether these outcomes have been achieved as a result of the TtL grant? How do centres find applying the five principles of the TtL grant?

Support workers record carers’ personal outcomes. This serves a human and an administrative function. Workers recognise the value of the carer’s story and ‘holding it’ for them. Carers centres usually report case studies and gather feedback from carers through evaluation forms and focus groups. They often show the qualitative difference short breaks have made to someone’s life. Reporting is aided by the TtL principles (see appendix 2) which help to structure reports and support the centres’ own organisational goals and outlook.

7. Conclusion

Overall, our findings support the argument that grant schemes like Time to Live are allowing carers and centres to challenge what respite funds are traditionally used for. They also emphasise the benefits of using funds in creative ways that are personalised to carers' needs.

Crucially, access to short breaks is embedded in a myriad of support that carers centres offer, which equally impacts carers' lives in a positive way. The difference 'pockets of respite' made was clearly demonstrated through the stories as carers described short breaks and support as 'a safety valve', 'a lifeline', 'a godsend'.

Going forward, funding for alternative short breaks should coexist alongside more traditional forms of respite (e.g. time away and replacement care) and ongoing support from carers centres, allowing carers to experience more holistic and sustained outcomes.

As a result of COVID-19, many carers have taken on longer and more intense caring roles and there is strong evidence (Carers UK, 2020) to suggest that the pandemic has, and continues to have, a disproportionate impact on unpaid carers. It has been a particularly challenging time for unpaid carers and carers centres, but the centres quickly adapted to different ways of working and came up with new and creative ways in which carers might have short breaks. It is clear from this study that 'the right break at the right time' is different for different people; the carers' stories and responses from carers centres evidence the need for, and success of, a flexible approach to what constitutes a short break.

The findings of this study indicate that the TtL grant scheme has had a very positive impact on unpaid carers' personal outcomes during the COVID-19 pandemic and that flexibility in approach to what constitutes a short break provides useful lessons for the future of short break provision. Previous research has tended to focus on services for the cared-for person that provide a respite effect for the carers, but this study has focused not only on the impact of short breaks provision, but also on the impact of alternative short breaks that move away from traditional service models. The research undertaken has shown that TtL grants have helped carers consider their outcomes and have been a catalyst for carers to pursue hobbies, interests and other activities that have contributed to their own good health and mental wellbeing.

The support provided by carers centres encouraged carers to focus on activities with lasting benefits over quick fixes, ones that enabled them to embed 'pockets of respite' into their everyday lives. The sustainability of these alternative forms of short breaks demonstrates that longer term benefits can come from short breaks which originate from carers' personal interests, and how new learning can lead on to other activities.

The findings of this study have implications for funders and delivery partners of micro-grant schemes like TtL but also more widely across health and social care in light of the Feeley Review (2021), which emphasised the need for outcomes to be at the heart of sector transformation.

8. Appendices

APPENDIX 1: EVIDENCE REVIEW: SHORT BREAKS AND CARER OUTCOMES

Many people identify as carers at different points in their lives (Seddon and Prendergast, 2019). In Scotland, existing legislation enshrines the rights of carers to access support – Carers (Scotland) Act 2016. The Act gives carers the right to an adult carer support plan or young carer statement. This aims to identify each carer's personal outcomes and needs for support through meaningful conversations with individual carers.

RESPITE CARE AND 'SHORT BREAKS'

Many carers still do not have any support and respite from their caring role (Seddon and Prendergast, 2019). Breaks from caring responsibilities are recognised internationally as essential to support carers' health and enhance their resilience to care (Roberts and Struckmeyer, 2018).

Historically, the term 'respite care' has been used in the literature concerning short breaks for families with a child with an intellectual disability (Tait and colleagues, 2017). However, more recently, 'short breaks' has become the preferred term, partly to move away from the negative connotations of carers requiring respite from their cared-for person, and also because short breaks now encompass a much wider range of supports than just placements in specialist residential facilities (Welch, 2011).

Re-thinking respite (The Older People's Commissioner for Wales, 2018) calls for a fundamental shift in the way respite care is conceptualised and delivered. It suggests that opportunities for a short break are taken together and / or apart, and that there is support for family and personal relationships, so that the carer and supported person can live as 'ordinary a life' as possible (Seddon and Prendergast, 2019).

WHAT RESPITE CARE IS AVAILABLE?

In Scotland, Shared Care Scotland (2021) highlights the different ways that breaks can be provided. Nowadays, short breaks are increasingly tailored to meet each individual carer and supported person's needs, and mark a gradual shift towards a wider range of short break opportunities that offer greater choice and flexibility.

Caulfield and colleagues (2021) also show that in Wales local ‘respitality’ 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 carer’s charity organised a group hotel or spa break, staff would accompany, organise transport and be there ‘if they need to talk to somebody’.

SHORT BREAK USE AND FUNDING

In relation to use of short breaks, Welch and colleagues’ (2011) study on short breaks for families of children with disabilities showed that:

- Many carers used more than one type of break. Breaks included leisure activities, overnight breaks, centre-based breaks and breaks that took place at home or in community settings (not mutually exclusive categories).
- In total, families received an average of 570 hours of short break support per year, although this varied from one hour per year to 4,290 hours per year. 53.8% of families used 400 hours or less of breaks per year; 28.6% used 200 hours or less per year; and 16.8% used 100 hours or less per year.
- 20.5% of families had experienced being turned down for at least one short break. 9.3% of children had been excluded from at least one short break and 8.3% of carers stated that their child was currently on a waiting list for a break.
- Leisure and play short breaks were used by 62.5% of families (for an average 123 hours per year).
- Overnight short breaks were used by 54.2% of families (for an average of 603 hours per year).
- Paid carer but non centre-based short breaks were used by 57.1% of families (for an average of 361 hours per year).
- Centre-based short breaks were used by 41.1% of families (for an average 506 hours per year).
- Almost a quarter (24.7%) of family carers used unpaid carers for short breaks (for an average of 226 hours per year).

Many families used breaks funded by several sources: 67.3% of families had breaks which were funded by local authorities; 10.9% had breaks funded by health authorities; 19.8% of families had breaks they funded themselves; 16.0% of families had breaks funded by other sources including charities and other government sources; and 29.4% of families received direct payments to fund short breaks (Welch and colleagues, 2011).

Carers UK (2021) compiled a resource which details how carers used their breaks during the pandemic. They found carers used short breaks funding for:

- Taking some exercise (e.g. a walk, exercise class, run) (37%)
- Completing practical tasks or housework (33%)
- Attending to personal medical appointments (e.g. going to the GP / dentist) (26%)
- Focusing on wellbeing (e.g. reading a book, time to myself) (26%)
- Catching up on sleep (25%)

WHAT CONSTITUTES A GOOD SHORT BREAK?

Staff from Wales (Caulfield and colleagues, 2021) found that breaks that supported a bespoke, meaningful break experience for the carer and their supported person had the following characteristics:

- Breaks align with personal preferences (e.g. the caring dyad can experience a break together or separately)
- There was flexible provision (i.e. regular provision balanced with a break 'as and when needed')
- Carers could plan a break in advance
- There was consistency between break provider/care staff to establish a trusting, caring partnership
- The break was appropriate to the person's circumstances and tailored to their interests, to support meaningful engagement
- Providing the break was sustainable, so the benefit is cumulative

Grant schemes like TtL (2019) also emphasise the need to challenge what respite funds are traditionally used for, and argue for the importance of using the funds in ways that suit carers' needs. This might mean funds can be used not only on time away and holidays, but to support hobbies and interests that make the carer's life more fulfilling, such as physical exercise equipment and hobby activities (Shared Care Scotland, 2021).

As a result, personalised short breaks are finally becoming associated with bespoke, outcome-led approaches to help carers achieve the things that matter most to them, and those they support, as previously urged by the Scottish Government (2008).

BARRIERS TO ACCESSING BREAKS

Welch and colleagues' (2011) study highlights that problems using short breaks fell into five areas:

- Resources
- Processes
- Information
- Family factors
- Child factors

Some carers, however, were reluctant to use short breaks and were concerned about whether short break providers would cope with their child or provide a suitable service (Welch and colleagues, 2011). The report details how carers considered short breaks to be suitable and unsuitable for their families, particularly in terms of issues of staffing; personnel; venues and facilities; systems and structures; care and activities; as well as sufficiency of breaks and the fact that some short breaks were not seen as providing a true break for the carer (Welch and colleagues, 2011).

WHAT KINDS OF OUTCOMES MATTER TO CARERS?

Thomas and colleagues (2017) provide a meta-review of different outcomes that have been considered in researching carers' wellbeing. It becomes clear from the literature that many of these different outcomes are interrelated in carers' lives.

Physical health

Physical health studies often explored carers' physical distress, physical functioning, somatic complaints, perceived or subjective health status, and sleep improvement.

Mental health

Mental health was another commonly researched outcome. The terms 'depression', 'anxiety', 'psychological distress' and 'self-efficacy' were commonly used.

Coping (burden and stress)

Burden, stress and coping are another common outcome considered by previous research, however, they were not always well-defined outcomes.

Satisfaction

Satisfaction with the short break intervention is another key outcome mentioned in the consulted literature (Thomas and colleagues, 2017).

Wellbeing and quality of life

Besides the general terms of wellbeing and quality of life, various others were used to describe this outcome. These included social isolation, social support needs, caregiving experience, sleep quality, marital–family relationships, social functioning and ability to perform activities of daily living (Thomas and colleagues, 2017).

Ability and knowledge

Definitions of this outcome included the carer's sense of competence or mastery, decision-making confidence, knowledge of the condition of their supported person, information needs and learning new skills (Thomas and colleagues, 2017).

The following section considers how these outcomes are impacted by short breaks and respite care.

OUTCOMES FOR CARERS AND SHORT BREAKS

Seddon and Prendergast (2019) review much of the existing research on how short breaks impact carers' outcomes.

Carer health and wellbeing

Seddon and colleagues (2021) found that although there is some research to suggest that personalised breaks can support positive health outcomes (Washington and Tachman, 2017), including improvements to carer physical health (Wilz and Fink-Heitz, 2008) and mental health, the evidence base could be too limited. Shaw and colleagues' (2009) systematic review of respite care provision for older people identifies various positive outcomes relating to health and wellbeing, including improved carer morale. Meanwhile, Victor's (2009) systematic review of UK interventions for carers concludes short breaks lead to improvements in carer emotional wellbeing, with feelings of normality, freedom, peace of mind and relief, albeit, tempered by a sense of anxiety, sadness and guilt.

Studies report improvements in carers' emotional wellbeing by taking short breaks, having been exhausted and rundown before their break and often citing that they need time to relax away from the demands of the caring role (Laing, 2013). Research by O'Connell and colleagues (2012) reports that four-fifths of carers experience lower stress levels after a short break. In contrast, other studies report short breaks deliver only positive physical but not positive emotional outcomes (King and Parsons, 2005), while others conclude that any positive benefits accruing from a break soon dissipate (McNally, 2013).

Increased stress

Alongside the positive health outcomes, research confirms that some carers taking short breaks report feelings of guilt, anxiety, emptiness and loneliness, particularly when the break takes the form of residential respite care (Salin and Åstedt, 2007; Roberts and Struckmeyer, 2018), as well as sadness at being separated (Victor, 2009). Brimblecomb and colleagues (2018) also argued that overall, respite care doesn't always lead to positive wellbeing outcomes.

Victor's (2009) review of 107 UK studies is typical in concluding that although carers showed satisfaction with breaks, and perceived benefits to their emotional wellbeing, there is little robust quantitative evidence of improvements to emotional wellbeing, and in fact, several studies show negative effects on carers' emotional wellbeing. This could be because of feelings of guilt (Tait and colleagues, 2017). Jardim and Packenham (2009) also found that a respite care group reported a decrease in burden, but unexpectedly also reported an increase in stress.

A life of their own

For some carers, short breaks afford opportunities to undertake routine domestic chores and mundane tasks, including going shopping and meeting basic self-care needs (such as sleeping and attending their own medical appointments), rather than pursuing outside interests or spending time with friends and family (Greenwood and colleagues, 2012; O'Connell and colleagues, 2012).

Positive relationships with the supported person

Research confirms that short breaks play a key role in supporting positive caring relationships and that they enable carers to continue caring (Victor, 2009; Shared Care Scotland, 2012; The Older People's Commissioner for Wales, 2018). Affording much needed space, short breaks enable carers to positively frame their relationship with the supported person, their caring role and their achievements (Roberts and Struckmeyer, 2018). Interestingly, following a break, carers report renewed commitment to their caring role.

Choices in caring

There is limited research looking at how short breaks might impact carers' choices, including limits to the caring role. Some studies suggest short breaks play a key role in delaying admission to nursing or residential care (Shared Care Scotland, 2012) but there is too little research to draw firm conclusions. For example, Mason and colleagues' (2007) systematic review, looking at different models of respite care, concludes there is no reliable evidence that short break interventions influence choices about caring, including preventing or delaying entry to nursing or residential care.

Satisfaction in caring

Research concludes that short breaks can contribute to carers' satisfaction if they offer some type of educational experience and an opportunity to learn from other carers (Seddon and Prendergast, 2019). This can help develop carers' confidence and a greater sense of overall satisfaction in their caring role. Gitlin and colleagues (2006) also report on a day care service that offers support and education to carers to improve carer confidence in managing complex behaviours. Carers using this short break day care facility reported improved wellbeing, reduction in depressive symptoms and a decreased sense of caring pressure.

In terms of satisfaction with short breaks (Welch and colleagues, 2011) highlight that:

- Carers' satisfaction is highest regarding the staff involved in providing breaks and lowest regarding the bureaucratic processes involved in accessing short breaks.
- Generally, children with additional support needs accessing breaks report positive experiences in terms of activities, relationships and confidence or independence. Interestingly, these themes are also reflected in the aspects of breaks that they did not like.
- Siblings' opinions of short breaks are also generally positive. Siblings want their brothers and sisters to have a safe and enjoyable break. They also report benefits for themselves from having a break, being able to do a wider range of things and receiving more attention from their parents. Siblings also disliked some aspects of short breaks, including being worried about their brother or sister while they were away, missing their brother or sister, feeling guilty about enjoying themselves without their brother or sister and missing out on the fun their brother or sister was having.

Collins and colleagues (2014) revealed that short breaks were crucial in helping parents with disabled children continue to provide care and Arksey and colleagues (2005) found a similar outcome for carers of people with dementia. This was often accompanied by other positive outcomes such as reducing social isolation and making time to care for non-disabled siblings among parent carers (Collins and colleagues, 2014).

WHAT MATTERS FOR CARERS IN A SHORT BREAK

The quality of the short break experience

The quality of the short break experience for the supported person is important in determining how carers themselves feel about the experience (Shared Care Scotland, 2012; McDonald and Macleod, 2016). In particular, carers value the safety of their supported person and the opportunity for meaningful engagement. Indeed, research suggests this lessens carers' sense of guilt (Stirling and colleagues, 2014).

The importance of choice and flexibility

An evaluation of the Scottish Short Breaks Fund projects notes that personalisation and choice, for both the carer and the supported person, are crucial for carers' outcomes (Shared Care Scotland, 2012). The importance of choice in short breaks provision to address varied needs and preferences is also highlighted by Shared Care Scotland (2010). For example, some carers express a wish for a family holiday rather than the break that is offered.

Both duration and frequency of respite breaks are relevant when assessing the importance for the carer and their supported person, but although carers highly value such services, this does not systematically translate into better outcomes for carers (Brimblecomb and colleagues, 2018).

Costs and savings

Both reviews of cost-effectiveness identified in the Parker and colleagues (2010) meta-review find no evidence of cost effectiveness for respite care. The Action for Children and the Every Disabled Child Matters Campaign (2009), however, argue that short breaks do lead to financial savings for the state as they reduce the chance of disabled children being placed in care, and help reduce health costs from reduced stress of the parents, families and carers. The lack of more conclusive evidence could be due to the methodological challenges of measuring cost effectiveness. Equally, as short breaks are by definition services provided for a short length of time, they may only be sufficient to provide temporary relief rather than any substantial improvements before returning to an often very demanding caring situation and the same intensity of care hours, a key factor in poorer mental health (Brimblecomb and colleagues, 2018).

Making short breaks work for carers – what's needed?

Mansell and Wilson (2014) found that most carers reported that their respite needs were not being met. Unmet needs were hampered by the lack of information regarding criteria for access to respite. Discrepancies were clear between professionals and carers on a shared definition of respite care. Carers were unsure of exactly which activities made up respite care and for whom the service was being provided.

Teo, Kennedy-Behr and Lowe (2018) conclude that better communication and collaboration between service providers and users, more targeted training of workers, and embracing a person-centred and family-centred approach to respite services, are needed. In addition, clearer definition and communication of respite services are required to best support families of children with significant disability in their home.

Different carers may need different interventions or combinations of interventions depending on the level and type of care needed by the care recipient and carer's broader circumstances, such as age or economic status (Brimblecomb and colleagues, 2018). Furthermore, the nature of support needed is likely to change as care needs and carers' personal circumstances change. Many studies, reviews and reports conclude that a combination or 'multiple choice' of interventions may be most effective in supporting carers and helping to meet the diverse needs of carers and people with care needs (Brimblecomb and colleagues, 2018; Seddon and Prendergast, 2019).

Thomas and colleagues (2017) conducted a quantitative meta-review of outcomes for carers. Their findings echo many of those discussed above. They also include the perspective of two carers on the many studies about carers' short breaks. Interestingly, the two carers highlight some key issues with many existing interventions:

- Carers of people with different conditions encounter different caring experiences and trajectories. Thus, what might be useful for one carer might not be useful for another. Similarly, what might be effective at one stage in the trajectory might not be effective at another stage.
- Variations in caring situations and across carers made it difficult to see that a single intervention could be the 'answer' in supporting carers. Rather, as one carer put it, 'because of the complexities of the situations, there is unlikely to be a one-size-fits-all that will be right at any given time'. As a result, the carer felt that any opportunity to engage with carers and the cared-for person might 'just press the right supportive

button at that moment', and hence a 'pick and mix' approach, whereby various support options were on offer, would be the ideal.

- The interventions that the high-quality reviews suggested might have a positive effect on carers, but the carers pointed out that what was actually available to carers was limited and incomplete. Although education and training for the carer might have a part to play, this was no substitute for 'direct intervention on the carer's own behalf'. They also raised the value to carers of standard services, including respite, that were provided to the person they cared for.

APPENDIX 2: PRINCIPLES OF THE TIME TO LIVE GRANT SCHEME

- **Mutual benefit**: all projects should make a positive difference to the lives of carers and the people they care for, improving their quality of life and wellbeing, and supporting the caring relationship.
- **Personalisation**: all projects should ensure that carers and the people they care for are actively engaged in the planning and decision making about any short breaks. We would encourage projects to always aim to deliver short breaks that are genuinely personalised and provide the right break at the right time.
- **Targeted support**: all projects should seek to make a difference to people who most need support. This may include cared-for people with multiple support needs and/or whose needs are not met by current models of service provision; carers who have a substantial caring role; carers who are less likely to access current support; or carers whose needs are not met by current models of service provision.
- **Adding value**: all projects should complement, and not replace or duplicate, the range of services which local authorities, the NHS and other agencies already fund or provide.
- **Knowledge and understanding**: all projects should be open to sharing learning and practice and help build a common evidence base that increases our understanding of short breaks and how they support the caring relationship.

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