



# **Final Evaluation of the DTNI Short Breaks Pilot Project**

## **Summary Report**

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## Contents

1. Overview of the DTNI Short Breaks Pilot Programme (SBPP).....	3
2. SBPP Logic Model .....	3
3. Performance Against Participation Targets .....	6
4. Primary Research Findings – Family Carers .....	8
5. Primary Research Findings – People Living with Dementia.....	12
6. Primary Research Findings – Interviews with Formal Care Givers.....	13
7. ‘Headline’ Conclusions .....	14
8. Lessons Learned and Recommendations for Embedding/ Mainstreaming.....	15
9. Next Steps.....	18

### MORROW GILCHRIST ASSOCIATES - IMPORTANT NOTICE

*This is a summary report of the Final Evaluation of the DTNI Short Breaks Pilot Programme. The Final Evaluation is the third stage in the three-stage evaluation of the SBPP. It builds upon, updates and consolidates the findings of the previous baseline and mid-term reports focusing on overall performance and impact. It was developed based on data and information provided to Morrow Gilchrist Associates and Geraldine Horgan by the DTNI Programme Team, alongside information derived from a programme of primary research and engagement over the three stages - with informal / family carers; formal care givers; people living with dementia, contracted service provider organisations; HSC Trusts and the DTNI Programme Delivery team. The procedures we carried out in performing the work that forms the basis of this and previous baseline and mid-term reports did not constitute an audit. As such, the content of this report should not be considered as providing the same level of assurance as an audit. It should be noted that the information contained in this report is subject to change as a result of changing circumstances and factors and is based on circumstances, data and information available at the time of drafting (November 2017). Only the final version of the full evaluation report should be considered definitive. Morrow Gilchrist Associates and its associates does not accept any responsibility or duty of care to any person to whom the report is shown and its use and interpretation should always be solely at the risk of the user.*

### ACKNOWLEDGMENTS

*The evaluation team would like to thank all of those who provided input to the evaluation process including informal / family carers; formal care givers; people living with dementia, contracted service provider organisations; HSC Trusts and the DTNI Programme Delivery team.*

## 1. Overview of the DTNI Short Breaks Pilot Programme (SBPP)

The Dementia Together NI (DTNI) project entails an investment of £6.25m by Atlantic Philanthropies, the Executive Office (TEO), the Department of Health (DoH) and the Public Health Agency (PHA) over a three-year period from 2014 to 2017. It aims to transform the commissioning, design and delivery of dementia services in order to improve the quality of care and support for people living with dementia, promote better awareness, reduce the stigma attached to the condition and improve the skills and competency of those working in dementia care services. It was designed to be in keeping with the strategic recommendations of the *Regional strategy for improving dementia services in Northern Ireland* (2011)<sup>1</sup>.

Morrow Gilchrist Associates (MGA) in association with Geraldine Horigan were commissioned by The Atlantic Philanthropies to conduct an ongoing evaluation of the Short Break Pilot Project, known as DTNI SBPP. The evaluation was undertaken in three main stages, baseline (completed in February 2017), mid-point (August 2017) and final (November 2017), all geared to investigating the impact of the SBPP on participating family carers and people living with dementia and distilling learning to provide meaningful guidance and recommendations to policy makers on what happens next for short breaks provision in NI. This is a summary of the Final Evaluation report.

The SBPP was shaped via a Scoping Study<sup>2</sup> completed by the DTNI team in 2015. The Scoping Study highlighted that there was a range of issues with the availability and appropriateness of respite/short break provision prevailing at the time. For instance, there was evidence that respite in an institutional environment was not always appropriate for people with dementia (with carers reporting increased levels of stress during and after a person with dementia returns from such a break). Furthermore, it reported that those who care for people with dementia are not getting sufficient support to enable them to carry out their caring role, and that the significant mental and physical impact of caring could lead ultimately to the deterioration of carers' health and earlier admissions to long term care for the person living with dementia. The scoping study concluded that that people living with dementia and their informal caregivers placed a high value on short break services. It further highlighted that there was clear research evidence of and commitments in successive HSC strategies/policies to expand the range, frequency, quality and flexibility of short break provision in Northern Ireland.

In response to the scoping report, the DTNI team sought to test more innovative, flexible and non-institutional models of support for people with dementia and to inform improvements to mainstream short breaks provision. In March 2016, DTNI commissioned four innovative, person-centred short- break pilot projects including home support services, extended domiciliary care, emergency support services and enhanced day opportunities. The target groups for these services were people living with dementia and their family carers, including younger people living with a dementia, people at an early middle or end stage of dementia, and people with a dual diagnosis of learning disability and dementia. Table 1 overleaf summarises the four pilots.

## 2. SBPP Logic Model

Figure 1 (on Page 5) sets out the agreed logic model for the SBPP<sup>3</sup>, which is the reference framework within which to assess the performance and impact of the pilot programme. All of the various primary research tools deployed within the evaluation were designed to align with this logic model, to facilitate aggregation of findings and reporting against key metrics. From the perspective of outcomes, this evaluation has assessed performance and impact in terms of its short-term outcomes as the pilot interventions, whilst coming near to closure, are still servicing the current needs of family caregivers. All four pilots ceased to accept new referrals / new service users in September 2017.

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<sup>1</sup> <https://www.health-ni.gov.uk/publications/improving-dementia-services-northern-ireland-regional-strategy>

<sup>2</sup> Scoping Report on Short Breaks and Support to Carers' (McCann, 2015)

<sup>3</sup> Evaluation Framework & Outline Methodology for Dementia Together NI Short Breaks Pilot Project (Prof. A Ryan, 2016)

Table 1: SBPP Interventions

<p><b>Home Support Services</b></p> <p><i>Contracted delivery organisation: Bryson Care</i></p>	<p>To be delivered to a total of 40 service users in the South-Eastern Health and Social Care Trust (SEHSCT), divided into three cohorts as follows:</p> <ol style="list-style-type: none"> <li>1. Provision of an <i>enhanced befriending</i> service including the provision of personal care services to 20 people living with a dementia for a period of 2-4 hours once per week from time of allocation to the end of the contract period.</li> <li>2. Provision of a <i>night sitting</i> service including the provision of personal care services to 10 people living with a dementia, once a week from the date of allocation to the end of the contract period.</li> <li>3. Provision of an <i>enhanced befriending</i> service including the provision of personal care services for a period of 2-4 hours and a <i>night sitting service</i>, including the provision of personal care services, to 10 people living with a dementia once a week from the date of allocation to the end of the contract period.</li> </ol>
<p><b>Extended Domiciliary Care</b></p> <p><i>Contracted delivery organisations: Homecare Independent Living, Trackars Ltd and Glen Caring Services</i></p>	<p>Services for people living with dementia including the provision of a comprehensive service (including personal care) for periods including overnight of up to a maximum of 4 consecutive 24-hour periods. Service to be provided to a minimum of 120 people living with dementia and their family carers. i.e. 24 across all Trusts. Overall benefit for individual service users capped at 168 hours. Entails an intensive lead-in assessment by providers to build relationships with the person living with dementia and his/her family carer in advance of providing the service.</p> <p>It should be noted that additional flexibility was permitted (post January 2016) in the way that families could access the Extended Domiciliary Care service, arising from discussions between the HSCB and the Trusts. The model of delivery, based on the contract specification, was for a single short break of 4 nights/ 5 days within one week i.e. consecutive. Informed by the nature of demand / early pilot experience, additional flexibility was granted in the delivery of this post January 2016, for instance to split the single break of 4 nights/ 5 days into two breaks of 2 nights/ 3 days in different weeks.</p>
<p><b>Emergency support services</b></p> <p><i>Contracted delivery organisation: Trackars Ltd</i></p>	<p>Personal care for periods from 1 hour up to 8 hours for a maximum of 3 consecutive days (24 hours in total). Delivered in Northern Health and Social Care Trust (NHSCT). Care provided within one hour of receiving a call to dedicated telephone line. No targets in that an emergency/ reactive service.</p>
<p><b>Enhanced day opportunities</b></p> <p><i>Contracted delivery organisation: Bryson Care.</i></p>	<p>This service was to be provided once a week to 23 people living with dementia and their family carers, including personal care for periods from 4-6 hours. Piloted in the Western Health and Social Care Trust (WHCSCT) only. The main focus on person living with dementia but spouse and family may participate. Focus on day opportunities but can include evening and night time activity e.g. attending concerts. Service will be delivered primarily outside the home and should incorporate enhanced befriending and personal care.</p>

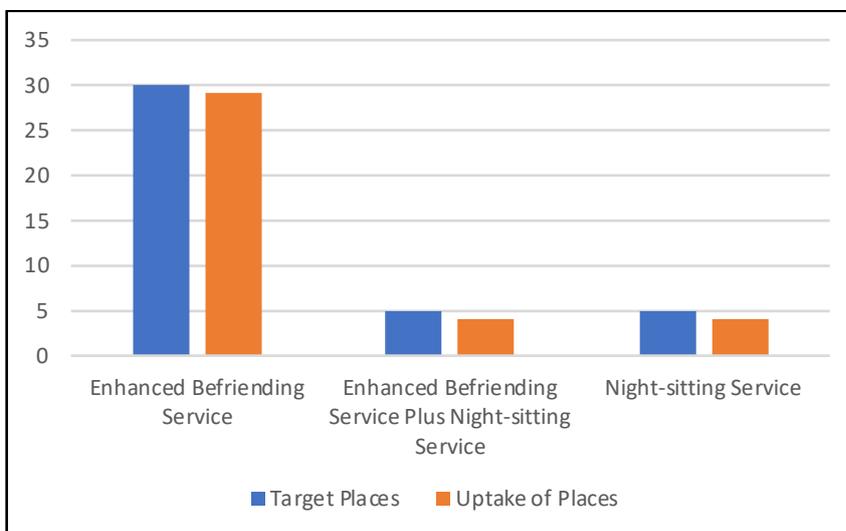
**Figure 1: Logic Model for the SBPP**

Inputs	Outputs/ Targets		Outcomes		
	Activities	Participation	Short	Medium	Long
<p><b>Staff</b> Service Providers DTNI Formal Carers Key Workers</p> <p>NI Executive and AP Funding</p> <p><b>Partners</b> 5 Health and Social Care Trusts (HSCT) across NI, Atlantic Philanthropies, HSCB, Department of Health, The Executive Office</p> <p>Evaluation</p>	<p>Conduct a scoping exercise to ascertain existing levels and types of short break provision for people living with dementia and their family carers</p> <p>Design a range of short break options to improve quality of life and wellbeing for people living with dementia and their carers</p> <p>Invite service providers to tender for the provision of four short break pilot options</p> <p>Implement the four pilots across the 5 Health and Social Care Trusts</p> <p>Conduct a longitudinal evaluation of the impact of the short breaks pilots, eliciting the views of service users, service providers and key stakeholders</p>	<p><b>Pilot 1:</b> Provision of home support services (including personal care) to 40 service users in the SEHSCT</p> <p><b>Pilot 2:</b> Provision of extended domiciliary care services (including personal care) for periods, including overnight, of up to a maximum of 4 consecutive 24 hour periods to 120 people across all 5 Trusts</p> <p><b>Pilot 3:</b> Provision of emergency support services (including personal care) for periods from 1 hour up to 8 hours for a maximum of 3 consecutive days (24 hours in total) in the NHSCT</p> <p><b>Pilot 4:</b> Provision of enhanced day opportunities once a week for periods from 4- 6 hours in the WHSCT</p>	<p>People living with dementia have their individual needs met through greater choice and access to respite support options</p> <p>Carers of people living with dementia have their individual needs met through greater choice and access to respite support options</p> <p>People living with dementia experience greater independence and reduced stress</p> <p>Carers of people living with dementia experience greater independence and reduced stress</p>	<p>Family carers report increased levels of satisfaction and reduced difficulties with their caring role</p> <p>People living with dementia report improvements in their health and wellbeing (physical, emotional and social) and quality of life</p> <p>Family carers report improvements in their health and wellbeing (physical, emotional and social) quality of life</p> <p>Family carers report higher levels of support in their caring role</p> <p>The quality of the relationship between people living with dementia and their carers is improved and maintained</p> <p>Lessons learnt are applied into mainstream dementia respite provision</p>	<p>New non-institutional short breaks options become embedded into mainstream services</p> <p>Family carers are supported to continue their caring role for as long as possible</p>

### 3. Performance Against Participation Targets

Figures 2-4 below set out the performance of each of the pilot areas against the target number of places for the pilot period as at 30<sup>th</sup> September 2017.

Figure 2: Home Support Service (SEHSCT)



There has been a healthy demand for places on the Home Support Service pilot. Discussions with the contracted service provider indicates that the ability to offer day-sitting / be-friending and night-sitting (or a combination of both) has worked in being flexible to the needs of each situation prevailing. This flexibility has enabled the service to evolve with the prevailing needs of service users. Specifically, the night-sitting service is typically used in situations where the person with dementia is at a more advanced stage in their journey with the disease.

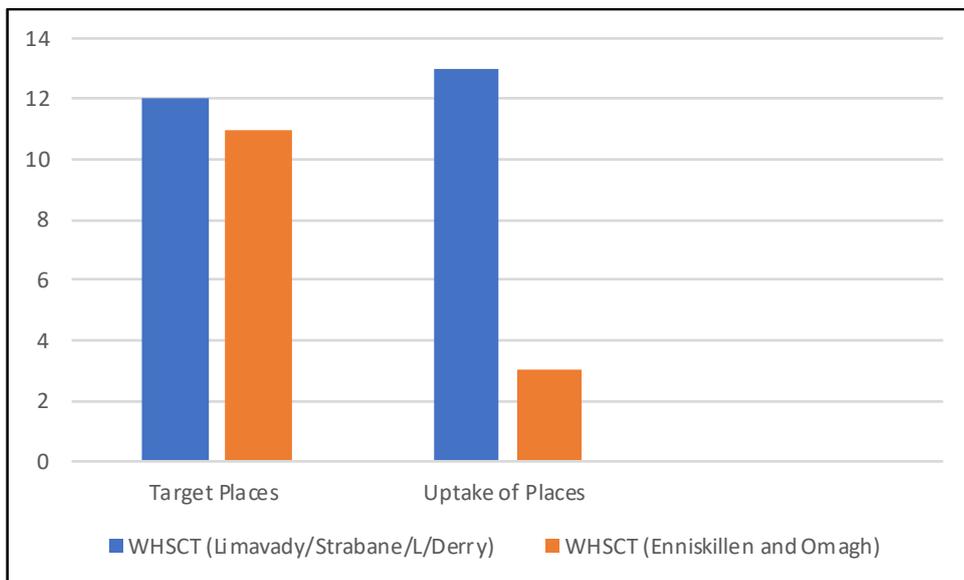
Figure 3: Extended Domiciliary Care (All Trusts)



The Extended Domiciliary Care service provides a full service (including personal care) in the home to support the person living with dementia, and facilitate the family carer to avail of a holiday/ short break from their caring role. The service was originally framed only around a single break of 4 nights/ 5 days within a single week (i.e. continuous) but more flexibility was allowed in the delivery since January 2016 with the ability to

split the allocated hours into two or more breaks. This served to create an upsurge in demand in the latter period of the pilot phase with 2 Trust regions taking on more service users than target places, and two others just one allocated place below target. The evaluation team has reviewed hours used per maximum hours allocated in each of the pilots for this service and it would appear that this flexibility has not significantly impacted on hours used. With the exception of one Trust region, there has been reasonable uptake of maximum allocated hours, particularly considering that many of the families joined in the latter half of the pilot. In these cases, if they did not require a continuous 4 night / 5 day break, it was difficult to use the maximum allocation of 168 hours when split over more than one break over the short number of months when they participated in the SBPP.

Figure 4: Extended Day Opportunities



The Extended Day Opportunities service was piloted in two areas in the WHSCT. The service in the Limavady/Strabane/L/Derry area was oversubscribed. However, the service in the Enniskillen and Omagh area, struggled to gain momentum, because it experienced difficulties recruiting sufficient staff in these rural areas to allow the delivery of the service. The problem with recruiting carers in this particular area was reported to be widespread across the WHSCT and caring sectors with issues involving low pay, mileage and time allowed to get between homes noted as contributing factors. This issue has proved very problematic as the Trust team made many referrals but because of the ongoing staff shortages the service provider has been unable to provide the service. The issue is not therefore one of low demand from potential users of the short breaks service, rather constraints in resourcing a service like this in these rural communities.

The Emergency Support Service as a reactive/ emergency service has been used by 53 families in the NHSCT during the pilot period, with one instance of a repeat referral of the same family. As a reactive/ emergency service there was no participation target set. Similar to other areas in the SBPP the picture in this service is one of rapidly increasing demand for the services, particularly within the latter period of the pilot programme. Improved communication and awareness raising of the service in recent months contributed to these increased activity levels.

Reflecting on trends across the four pilots, **considerable progress was achieved in relation to uptake of places across all of the SBPP** service areas since the baseline report stage in February 2017, where there was a concern highlighted that some participation targets may not be achieved. The upsurge in activity since this time, has been mainly due to increasing awareness of the pilots as they have progressed by key personnel in Trusts. In addition, it is clear that ‘word-of-mouth’ from families/ family carers availing of the

various services and who are very positive about the difference it has made to their quality of life/ the quality of life of their family member living with dementia, also contributed to the upsurge in activity as the pilot period progressed. A final factor contributing to this is that additional flexibility was permitted (post January 2017) in the way that families could access the services, arising from discussions between the HSCB, the DTNI Programme Team, the Trusts and the pilot providers, particularly in relation to the Extended Domiciliary Care pilot. This flexibility has worked to enhance the appeal of the service to a larger number of families and accordingly to increase uptake of places. The fact that it was facilitated reflects close and responsive contract management by the DTNI programme team.

**The pattern of uptake being ‘back-loaded’ within the pilot period, created challenges in terms of delivery pressures for contracted service providers.** It was reported to be difficult to recruit additional staff in the latter period of the pilot, in that with limited delivery time remaining, it was not possible to offer prolonged continuous work to individuals who may have applied. The timing of this upsurge in demand also meant that just when awareness of the value of the SBPP offer was gaining momentum, the service providers were at a point where they had to stop taking new referrals. By the summer months of 2017, most service areas had reached capacity/ contracted targets and had to focus on delivering services to the existing caseload for the remainder of the pilot period. In addition, with some ‘late joiners’ to the pilots as awareness of them spread, **having access to a really valued service for a short period of time and then no longer being able to access it, created further challenges.** (This is evident in the feedback from some of the family carers referenced later in this report). Finally, in all service areas with more demand materialising in the later period of the pilot there is a constraint in terms of families being in a position to avail of the maximum hours available for a pro-longed period of consecutive weeks (e.g. on the Home Support Service and the Extended Day Opportunities pilot) or within a short participation period in respect of the Extended Domiciliary Care offer.

Overall, it is the view of the evaluation team that **a pilot period of circa 18 months was arguably too short**, in that realistically it takes a lead-in time of 6 months to establish and promote new models of service delivery, before ‘business as usual’ delivery can happen. The DTNI team, the Trusts and the service providers worked to address constraints prevailing in terms of flexibility and awareness raising challenges in the early delivery period. As such, the fact that the majority of service areas met participation targets in terms of places and/or were oversubscribed is a very strong performance. It also evidences the fact that there is a **strong demand for person-centred, flexible and responsive services to support informal carers and persons living with dementia.**

#### 4. Primary Research Findings – Family Carers

The evaluation methodology at baseline, mid-term and final stages, incorporated the implementation of postal survey questionnaires with informal/ family carers. These were designed to profile the family carers and to capture details on their access to a break from their caring role prior to the SBPP (at baseline stage only) and to capture the carer’s self-assessed physical, emotional health and quality of life throughout the pilot period (i.e. captured at baseline, mid-term and final stages). Carers were also asked to complete two indices at multiple time points - the Carers’ Assessment of Satisfaction Index (CASI)<sup>4</sup> and the Carers’ Assessment of Difficulties Index (CADI).<sup>5</sup> In terms of response rates, 130 completed baseline questionnaires and of these 57 participated at mid-point and final point – allowing longitudinal tracking of their self-assessment measures.

The headline profile figures are as follows:-

- In terms of gender (62.3%) were female; and 49 (37.7%) male. The mean age was 66.7 and age ranged from 25-94 years. The mean length of time the carers had been caring for their family member was 5.6 years and this ranged from 0.5-48 years. The majority of carers were married (73.1%), retired (55.4%) and lived in the same home as the person they cared for (70.8%). More than a third of all the carers (37%) also had the responsibility of caring for others in addition to their family member with

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<sup>4</sup> which is a 30-item index which contains a series of statements that carers have made about the satisfaction that they derive from their caregiving role (the higher the score the higher the levels of satisfaction)

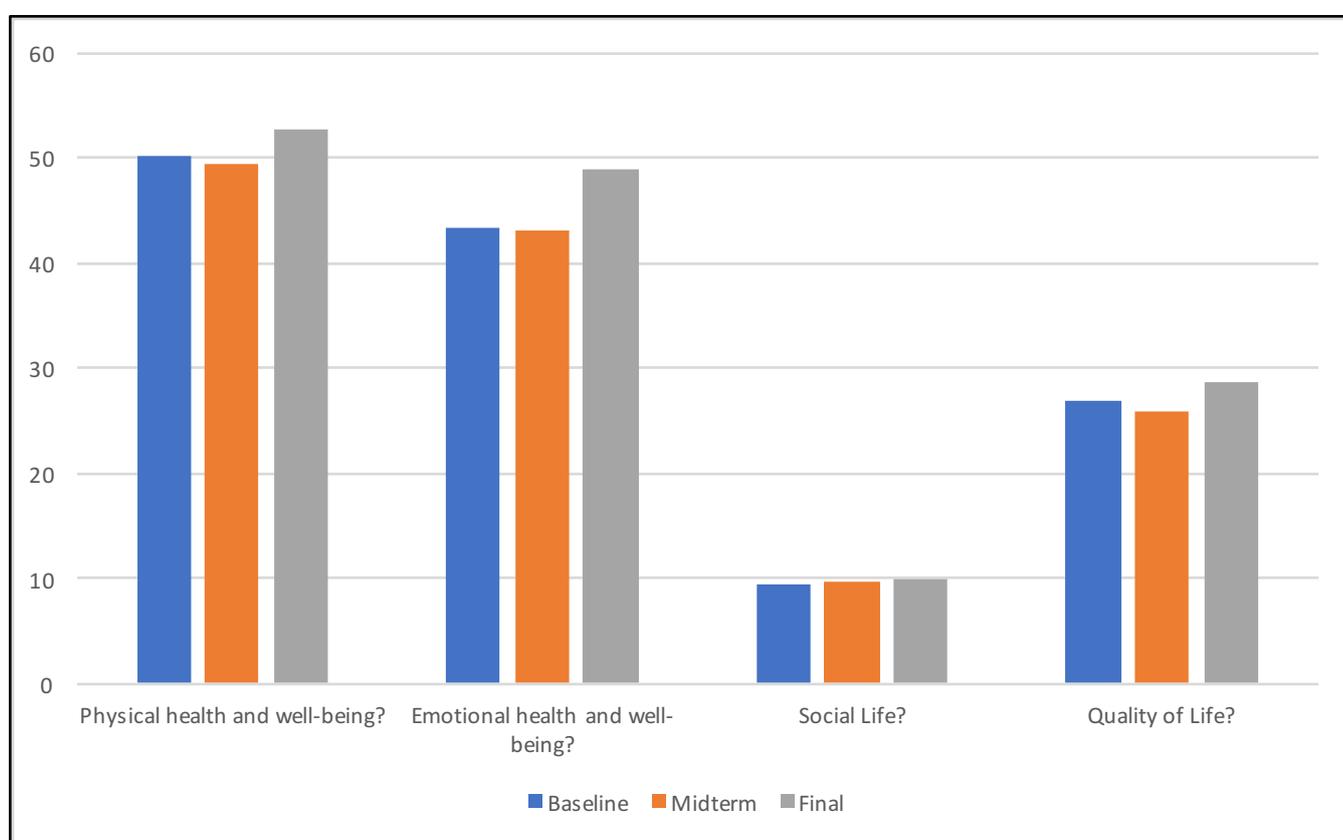
<sup>5</sup> which is a 30-item index which contains a series of statements that carers have made about the difficulties they faced in their caregiving (higher scores equate to higher levels of stress).

dementia, these included their children, grandchildren, parent(s) or parent(s) in law.

- Prior to the SBPP, 70-80% of the carers could either never or seldom access an overnight break or longer break away from their caring role. More than half were able to access a few hours (2-6 hours) away from their caring role with 38% citing this as being accessible 'sometimes' and 20% citing this as being accessible 'often'. This reflects the findings of the scoping study that was a precursor to the launch of the SBPP and informed its design. In effect, they confirm the need identified in the original scoping study to expand the range, frequency, quality and flexibility of short break provision in NI.

Overall no statistically significant differences were observed across the three time points for carers' physical health and well-being, emotional health, social life or quality of life. However, when men and women were observed separately, **female carers' physical health and wellbeing, and emotional health and wellbeing significantly improved over time** ( $P < 0.05$ ), and a small improvement in quality of life was observed across the three time points but this was not statistically significant. This is illustrated in Figure 5 below.

Figure 5: Female Carers (% who rated the variables as Very Good or Good).



**Male carers' social lives improved** across each time point, however no other significant differences were observed in male carers. The improvement in the social life of men is an important finding, in that it could eventually lead to an improvement in the other outcomes. This is in the context that it is recognised that older men can become more socially isolated, with less involvement in support and friendship networks, than their female counterparts.

These results should be interpreted in the context that it is possible that the carer's role may have evolved during the period of SBPP in that the person living with dementia may have experienced declining health over the period. With this in mind, and in triangulating these findings with one-to-one interviews with family carers, referenced below it is evident that **the SBPP has had a positive impact on physical and emotional health of carers in particular - albeit that this is more evident amongst female carers relative to male carers.**

It is evident from the mean satisfaction and difficulty scores over the three time periods (using the CASI and CADI indexes), that whilst carer difficulties have increased over the duration of the programme, the levels of carer satisfaction remained relatively unaffected. It may be suggested that the SBPP interventions have had an impact, in terms of **the ability to maintain carer satisfaction in the face of increasing carer difficulties and possible continued declining health in the person they care for**. This finding is reinforced by the interview feedback from family carers referenced later in this section. The table below summarises the most common items from the CASI and CADI questionnaires cited by family/informal carers as sources of satisfaction and stress during the course of the SBPP evaluation.

Table 2: Most Common Sources of Satisfaction and Difficulty

Most common source of satisfaction taken from the CASI Questionnaire	Most common sources of difficulty/ stress taken from the CADI Questionnaire
<p><i>'I am able to keep the person I care for out of an institution'</i></p> <p><i>'I am able to repay their past acts of kindness'</i></p> <p><i>'Knowing the person I care for the way I do means I can give better care than anyone else'</i></p> <p><i>'I am able to ensure that the person I care for has their needs tended to'</i></p> <p><i>'I get pleasure out of seeing the person I care for happy'</i></p> <p><i>'It nice when something I do gives the person I care for pleasure'</i></p> <p><i>'Maintaining the dignity of the person I care for is important'</i></p>	<p><i>'It is physically tiring'</i></p> <p><i>'It restricts my social life/outside Interests'</i></p> <p><i>'I don't have enough private time to myself'</i></p> <p><i>'The person I care for needs a lot of help with personal care'</i></p> <p><i>'My sleep is affected'</i></p> <p><i>'My emotional well-being suffers'</i></p> <p><i>'I can't relax because of worry about caring'</i></p> <p><i>'Some family members don't help as much as they could'</i></p> <p><i>'The person I care for is incontinent'</i></p> <p><i>'It can put a strain on family relationships'</i></p>

The evaluation of the SBPP was also informed by one-to-one interviews with 37 family carers at mid-term and final stages. The findings from these interviews indicate that the **SBPP services have been received very positively by the majority of those who were offered and availed of the services**. Some of the words used to describe the service included – *'It's a blessing'*, *'fantastic'*, *'excellent'*, *'great service'*, *'life saver'*, *'a life line'* and *'manna from heaven'*. The longer the service was availed of, the more benefits appeared to be gained e.g. less carer stress; less carer exhaustion; being able to keep their loved one at home (especially not having to put them into care for respite which was reported to be very disrupting for all involved); the carer being able to resume a semblance of a social life again; improved mood and behaviour of person living with dementia and good relationships formed between family carer, person living with dementia and formal carer.

The majority of the family carers also found the service flexible, tailored to their needs, and reported that they found the formal carers knowledgeable and highly skilled. For all services (except the Emergency Support Service<sup>6</sup>) it was emphasised that great care was taken to get to know the needs and interests of the person living with dementia and therefore the carers were more than happy to leave their family members in their care. Many of these family carers have had very little help before and, generally speaking, described that what is offered through the SBPP as 'life-saving'. The service was underpinned with excellent communication (both verbally and in the form of a diary, completed after each visit listing everything that had happened). It was highlighted that managers from the service provider organisations, inspired confidence in almost all the

<sup>6</sup> in that this is a reactive service there is not the opportunity for up-front intensive assessment

carers during the pre-visits. The **transformational nature of the SBPP support has helped carers to overcome previous fears of accepting help and support.**

The majority of those availing of the Extended Domiciliary Care services preferred to use it in shorter time frames i.e. full days, overnight or weekends with only two interviewed by the evaluation team using it for the originally envisaged 5 consecutive days. This suggests that the decision to enable flexibility around the original 4 night/ 5 day Extended Domiciliary Care offer has helped to align the service better with prevailing needs. The text box below illustrates the range of benefits gained from the SBPP as reported by the family carers and spans views captured at both mid-point and final evaluation stages. Some of these views are shaped by the impending closure of the SBPP and concerns about managing thereafter.

*"I have only just been offered the service and I want more, other outside care I used before left my mum distressed, I am very impressed with this service, please let it continue."*

*"Oh, my goodness, you have no idea how good this service is; manna from heaven, I never got out before."*

*"Whoever came up with this idea deserves a medal, way better than respite only problem is it is going to end."*

*"The formal carer comes every week, Friday evening and paints pictures with my father who was an artist, plays cards or watch movies, sometimes she takes my mother and father for walks along the beach, they love that. We my husband and I have our dinner out every Friday with our disabled son who also needs our time. It has kept this family together that break"*

*"This service has transformed my life, the formal carer collects my sister each week and takes her away for what feels like a whole day, my sister loves going with the carer who has gone over and above her duty, she takes her walks on the beach and for coffee, they play old music in the car and my sister comes back really happy and calm."*

*"The formal carer took my mum to her home on a farm, she loves animals and gardening and had she her patch of garden to tend. Mum going to miss her so much as they also went for walks and coffee, mum was a nurse and the carer was also a nurse so they had so much in common. We all learned so much from her."*

*"It is excellent as I had nothing before this, I use it – Emergency Support Service - for necessities as I care for very ill daughter in addition to husband with severe dementia. I use for hospital appointments, GP and A&E visits and not luxuries like hairdressers or coffee."*

*"I felt very isolated and unsupported previously, but now with the break things have improved and I also got a social worker. What will I do when it finishes?"*

*"The service is a life saver, before I was offered it I felt like a prisoner, fantastic."*

*"It was worth a billion pounds for me, I got to go away for my 60th birthday, it gave me my life back as I hadn't been anywhere for 10 years. I would pay for this every so often myself"*

*"I took a break at home and did all the things I have been unable to do for a long time. My sister came from Monday-Thursday and the short break started from Thursday to the following Monday. I caught up with sleep, was able to relax, got peace it was brilliant. If I thought I could look forward to it again every so often it would make life so much easier, I am always on red alert."*

*"Each week I get to go for a walk with my husband and go for a coffee and a chat, invaluable."*

*"Being able to spend time as a family each week, giving us a total break is fantastic, parents have multiple needs and we get to spend time with our autistic son. They asked us what we needed best and what days, hours- excellent service"*

*"My mother remembers the formal carer when she arrives every Sunday, while the purpose is for her to go out, we are working on that as no one can get my mother out of the house but it is looking very hopeful for her to go with the formal care giver... into town to what was her favourite café...the formal care giver calls here"*

*every Sunday for around 5 hours and I get to spend every Sunday having lunch with my family for which I have no words to describe the gratitude I feel, she even came on Christmas Day, how good was that?"*

*"The formal carer takes him to his place of worship each week despite being a different religion. I feel I can never repay this as going to church is of the things he remembers and enjoys."*

*"Not got for long enough, I want it to continue into the future."*

A small number of family carers (n=6) unfortunately felt they didn't fully benefit from the service with the predominant reason being that the support was being offered too late i.e. in the last month(s) or weeks of the pilot. Therefore, they only received the service for a very short time. In a couple of these cases, it was highlighted that these time pressures impacted on the space for the up-front intensive assessment of the needs and interests of the person living with dementia, effectively meaning that their needs and those of the family carer were not fully taken into account into the subsequent delivery of the service. In one case, it was reported that the service was cancelled at the last minute, leading to family carers having to cancel their break, which led to frustration and disappointment for the carer and the wider family. It should be noted that while **these carers in the main recognised the value of the SBPP offer it was the rushed nature of the delivery at the end of the pilot period, that was the major factor in their disappointment.** In addition, two of the family carers highlighted that the formal carers could have benefitted from more specific training (e.g. communication skills to interact effectively with the person living dementia, first aid). The text box below includes quotes from these family carers on the perceived weaknesses of the SBPP support.

*"We were unable to use our allocated hours only 32 out of 168 as some of the carers were no good. A carer just sat there with no interaction and one time we came back and carer was asleep. No stimulation, mum loved going to church but this wasn't explored. Very disappointed."*

*"They asked me what I wanted but could never get the days/hours I wanted. Different girls and didn't always get the chance to meet them all, concerned about their working conditions as one came off a night shift and into my mum."*

*"Excellent service but was first offered it as it was coming to an end, would have loved to have had a chance to meet the carers and for my husband to meet them prior to break but my family members said they were great."*

*"Wasn't able to use as planned as they let me down within 24 hours and I had to cancel my night away."*

*"It was wonderful...I am exhausted my life is on hold and it allowed me to get away for a few nights. Carers very nice but more training needed."*

*"Haven't been able to use this brilliant service much as only getting a few months...it was great...but then carer changed and on three occasions it has been cancelled. Great when it works but dependability important."*

## **5. Primary Research Findings – People Living with Dementia**

At the midpoint evaluation stage only four people living with dementia were able to take part in the interviews (all from the Extended Day Opportunities service) and of these two were unable to give sufficient information to enable a deduction. Of the two who could communicate, sufficient information was obtained to ascertain that the short break scheme was greatly welcomed and that they looked forward to the weekly visits from the formal caregiver. One person mainly used the service for outings with the formal care giver which were greatly valued and the other spent time each Sunday with the formal care giver in her own home, doing activities in the home and exploring areas of interest. In both cases, **family carers noted improvements in mood and behaviour** since the uptake of the SBPP and noted that the formal care givers were very well qualified in the way they communicated and engaged with their relative.

At the final evaluation stage, a further five people living with dementia participated in the interviews and had availed of the Extended Day Opportunities and the Home Support Service. **All five found the service excellent, enjoyable and really looked forward to the formal carer calling.** All but one remembered the formal carer's name, knew and looked forward to them coming each week and were highly involved in the activities that took place. Special bonds appear to have been made between the person living with dementia and the formal carer. In all cases the formal carer met with the family first to establish how best to work the service and the same carer attended each week thereafter. If the formal carer could not make a particular day, alternative days were agreed upon rather than a new formal carer coming. **Great care appears to have been taken to match the formal carer to the person living with dementia.** For instance, two former nurses with a passion for gardening were put together as were two outdoor animal lovers who loved going to farms and walks along the beach. One reported that they were able to do activities that they would not otherwise get to do (e.g. going to the cinema during the day when it was quieter). Again, of those aware that the short break had ended or was going to end very soon said they were going to miss it very much. Comments made by people living with dementia on the SBPP are illustrated in the text box below.

*"She/ the formal carer is very good to me and I like her"*

*"When she comes we knit, she reads to me and we sing. I might be going to the Café in a few weeks when I am ready"*

*"She took me to her house (farm) and her family to do gardening I love gardening and to see the animals, she took me to the beach and for coffee, I got to do things I wouldn't have otherwise."*

*"Bring it back I am really going to miss it and her."*

*"We are going to miss this so much the girl came every week and spent time with us, why is she not coming back, we went for walks and she loved my paintings, it helped C, she was able to go out."*

## 6. Primary Research Findings – Interviews with Formal Care Givers

The evaluation team conducted 22 interviews with formal care givers across mid-term and final evaluation stages. The majority of the formal care givers interviewed **spoke very highly of the service and appeared to be really proud to be a part of it.** Many were involved with several families and, where possible, they stayed with those families throughout allowing for continuity of relationship building and delivery of a service that was tailored to the needs of the family. They felt the variety of their job was great and the different levels of input and support required for each family enhanced and improved their caring abilities. All but one formal care giver spoke highly of their employer and the majority felt that they were very well supported in their work. All but one felt that the training they received for the job was at the correct level and adequate and all had completed the dementia awareness training. However, one formal care giver did not feel supported in their role, and did not feel that they were given sufficient background of the family and felt isolated. Another formal carer reported that she sometimes felt a bit vulnerable while sleeping overnight but it was just that she doubted her abilities. Several of the formal care givers were not fully aware that the SBPP was a pilot, nor could they name the service area they were working on, which evidences some of the challenges around communications and awareness raising that have been experienced during the pilot phase. Communication with management was also felt to be adequate and the majority felt supported in their role and kept up to date on job related issues. All worked with several families and where possible, they stayed with them for the duration of the pilot. They felt great relationships were formed with the person living with dementia and their families (some of whom have kept in touch after the support had ceased).

All of the formal care givers interviewed at both stages could see the benefits that the SBPP provided to families but expressed concern about what could happen to the families in the aftermath of its withdrawal. The main difference between the SBPP and other support was the ability to build in-depth relationships, the continuity of support, providing immediate help and the flexibility to fit in around the family. In effect, the whole **SBPP service is underpinned by a very person-centred engagement** that requires a depth of knowledge about the person living with dementia, their biography, hobbies and interests; family / household setting and

their current condition. This engagement is all geared to preventing premature disability or disconnection from life by the person living with dementia and simultaneously supporting benefits / improved quality of life for both the person living with dementia and their family carer. For SBPP service areas involving ongoing support over an extended period (e.g. Home Support Services, Extended Day Opportunities) it is clear that as the person progressed through their journey with dementia, the nature of the engagement and support provided by the formal carer giver adapted accordingly, indicating the value of continuity of relationship building with the same family.

Overall and overwhelmingly the same themes emerged from the primary research with from the formal carers, as per the findings from people living with dementia and family carers, that the SBPP has been an **exceptional, much needed, extremely appreciated service that has helped many families from its inception**. The longer the time availed of the better the benefits and the majority of formal care givers were of the view that it should be incorporated into mainstream care pathways as soon as possible.

## 7. Primary Research Findings – Interviews with HSC Trusts

The evaluation team interviewed representatives from four of the five HSC Trusts at the baseline and mid-point of the evaluation (March and August 2017), primarily to identify and resolve implementation issues (discussed above in section 3). At the mid-point, there was also an opportunity to seek their views on the services being trialled through the SBPP and their future. Trust representatives reported that they had received very positive feedback from family carers about how well the short breaks were meeting their needs, reflecting the direct feedback given to the evaluation team. They highlighted the distinctive features of the SBPP services compared with existing short breaks they were able to offer family carers. In particular, these related to the personal care aspect and flexibility of this service, the time to focus on intensive assessment of the interests, needs and abilities of the person living with dementia, and the opportunity to provide extended and/or regular breaks for the family carer in their own home. Trust representatives reflected that a simpler menu of options where families could access support via pre-agreed 'block of hours' and a clearer delineation of what the various SBPP services were (and were not) would have been beneficial. Given the value and impact emerging from the families who had accessed the service, there was a view from Trust representatives that the case should be made for this sort of provision to continue.

## 8. 'Headline' Conclusions

The 'headline' conclusions from the final evaluation of the SBPP are as follows:-

1. There is **strong demand for person-centred, flexible and responsive short break services** to support informal / family carers and persons living with dementia. Recognising some of the constraints and difficulties experienced in the early stages of the delivery of the SBPP (e.g. insufficient flexibility and awareness raising/ communication challenges), the fact that the majority of service areas met participation targets and/or were oversubscribed (in terms of available places) is a strong performance.
2. The **delivery model and ethos of SBPP concept are distinctive** to what is already on offer and traditional models of respite. Both fit strongly with the needs identified in the 2015 Scoping Study and the originating strategic/ policy drivers (in terms of both dementia policy and the HSC reform agenda).
3. Overall there is a **solid performance against all short-term outcomes**, in the SBPP Logic Model with a slightly more mixed picture on the performance against the medium-term outcomes, consistent with the stage of delivery of the pilot (e.g. application of lessons learned can only come at the end of a pilot programme).
4. There is evidence of **positive impacts on service users** (both the family carer and the person living with dementia) from the primary research conducted for this evaluation. This is also supported via feedback and input from contracted service delivery organisations and the HSC Trusts during the course of the evaluation work. The service has invariably been described as 'transformational' and 'a life-saver' by the majority of families accessing the same. All of this highlights quality and responsive contract delivery/ management and oversight by the delivery organisations, the DTNI programme

team and the Project Board.

5. Allied to the above, in effectively supporting their work, **the SBPP has contributed to family carers' ability to sustain their caring role.** In turn, this can significantly reduce or defer the need for long-term residential and nursing care. In the view of the evaluation team, based on the feedback from family carers, this is likely to be most relevant to the Home Support Service as it is delivered as an ongoing (weekly) service, rather than a single/ 'one off' short break. A comprehensive and robust cost-benefit analysis would be needed to explore the potential economic impact of delaying entry into residential care or preventing escalations towards hospital admissions. This was not part of the evaluation brief. However, a crude comparison of the cost of nursing home care and that of the Home Support Service, indicates that if the saving from avoiding the cost of a care home was to outweigh the cost of delivering the Home Support Service, the intervention would need to maintain the individual at home for on average 11.5 weeks. The evaluation has evidenced that investing in services such as this, that support people living with dementia to live well in their home and in their communities, promotes better quality of life and contributes strongly to family carers being/ remaining satisfied in their caring role.

## 9. Lessons Learned and Recommendations for Embedding/ Mainstreaming

In endorsing DTNI the Northern Ireland Executive and The Atlantic Philanthropies signalled their commitment to embedding the learning, new approaches and products developed through the programme into future provision so that sustained benefits could be realised for people affected by dementia. Specifically, the funding agreement with The Atlantic Philanthropies signed on behalf of the Department of Health in September 2014 included a specific commitment to furthering the outcomes of the programme via:

- planned transfer of responsibilities from project to mainstream staff;
- provision of additional recurrent funding to sustain products;
- activities or absorption of their costs into mainstream expenditure; and
- use of programme learning to re-shape patterns of mainstream expenditure

Deloitte are presently facilitating the development of sustainability plan, for the entire DTNI portfolio of activity, which is required to provide a suitable vehicle through which to **realise the shared ambitions for long-term change through the DTNI programme**, referenced above. Whilst this sustainability planning work is ongoing, the evaluation team engaged with Deloitte to exchange lessons learned from the evaluation of the SBPP and emerging directions within the sustainability planning exercise. This was with a view to sharing information about which elements of the SBPP have worked well and therefore should be embedded/ mainstreamed.

The sustainability planning work, recognises that there is **a need for momentum** – while short breaks pilots and learning are fresh and DTNI still has the Project Board to initiate. The evaluation team would concur with the latter point, particularly in that there has been significant momentum in the latter period of the SBPP in terms of uptake and demand, and a sense that many families have only been able to access the service for a short time and are now (potentially) losing a highly valued service. In highlighting lessons learned this should be done from two perspectives, first lessons for piloting an initiative of this nature (and for evaluating the same) and secondly recommendations for embedding/ future mainstreaming. The text box below sets out the main lessons learnt that are relevant to the first perspective.

1. A **pilot period of circa 18 months was too short**, in that realistically it takes a lead-in time of 6 months to establish and promote new models of service delivery, before 'business as usual' delivery can happen.
2. In terms of the evaluation design **two time points for surveys/ questionnaires with family carers would have been sufficient.** With the benefit of hindsight, and with the upsurge in demand in the latter half of the pilot, families were joining the SBPP quite late into the programme, and therefore fitting in a baseline, mid-term and final questionnaire was not feasible in many cases. There was significant feedback around survey fatigue within the evaluation process, which having two time points

only might have eased.

3. In terms of completion of the carer surveys (including CASI and CADI) a better approach might have been to have had the **evaluation team include completion of these surveys with the family carer as part of the home visit / interview** (rather than have these completed by the family carer and returned by post). This approach could still have facilitated independent input and may have helped address survey fatigue and misinterpretations/ gaps in the responses.

The key recommendations for embedding/ future mainstreaming are illustrated in Table 3 below along with supporting commentary and rationale.

Table 3: Recommendations for Embedding/ Future Mainstreaming

Recommendation	Commentary/ Rationale
<p>Short-breaks provision should be integral to the <b>new dementia care pathway and service model</b> under development.</p>	<p>A new dementia care pathway and associated service model are in development. It is understood that they have been presented to the Department of Health and subject to ministerial approval and the required investment to support implementation, the new pathways will be implemented over a five-year period. The new pathway aims to integrate the roles of Primary Care and Secondary Care (Memory Clinics) in both diagnosis and follow on care for people with dementia. Currently the majority of dementia diagnoses and follow on care are led by secondary care. It is understood that the new model aims to enhance the role of General Practitioners and Nursing in the assessment, diagnosis and following on care for people with Mild Cognitive Impairment and Early Stage Non-Complicated Dementia. Short-breaks provision has a key role to play in this model in terms of post-diagnosis care, helping family carers to sustain their work in helping their family member to live well in their home and in their community, promoting better quality of life (for both parties).</p>
<p>In embedding/ mainstreaming short-breaks provision into the new dementia care pathway and service model, support should be categorised as:-</p> <ol style="list-style-type: none"> <li>a. <b>continuous overnight support</b> (including personal care) to facilitate the family carer to enjoy an extended break/ holiday (where flexibility could apply for instance to split this into two weekends or the original 4 night/ 5 day break)</li> <li>b. <b>more regular (weekly) support via a flexible pre-agreed block of hours</b> to connect the individual living with dementia to interests and activities, either in the home or via outings in the community and that simultaneously facilitates a regular (weekly) break for the family carer for a few hours from their caring role.</li> </ol>	<p>A key observation of the evaluation is that there were too many labels/ titles for the different pilot services, adding additional challenges to awareness raising. It is clear that some service provider personnel were not aware of the other support strands on offer outside of the one that they were active in delivering. Similarly, many of the families interviewed were also unaware that they were participating in a pilot with multiple strands and what each offered.</p> <p>Outside of the emergency / reactive service offered by ESS, the support needed has fallen into two areas – firstly the continuous support offered via the Extended Domiciliary Care service facilitating a longer duration break for the family carer and secondly the more regular (typically weekly) support where a ‘block of hours’ is provided by a formal care giver to facilitate regular short breaks for the family carer and positive impacts for the person living with dementia. During the pilot, the latter is delivered via the Home Support Service (predominantly day-sitting) and the Extended Day Opportunities pilot. In practice, it is the view of the evaluation team that there has been overlap between these - the Extended Day Opportunities service can involve connecting</p>

<p>This applies over and above an <b>emergency support service</b>, which is valuable as an emergency/ reactive service in crisis situations.</p>	<p>persons living with dementia to interests and hobbies that can be enjoyed in the home if the individual is not ready/ does not want to pursue activities outside the home. Similarly, within the Home Support Service the formal care giver may support the individual living with dementia on occasions to enjoy an activity outside the home.</p> <p>It is view of the evaluation team that simplifying the categories of short break support available would assist in awareness raising and understanding for all concerned. It would also simplify the delivery and oversight of the services.</p>
<p><b>Self Directed Support</b> should be a key <b>enabling mechanism to replicate and scale up short-breaks provision</b> per the pilot approaches deployed in the SBPP.</p>	<p>Self Directed Support aims to give people who are assessed as needing social care support, more choice and control about how and by whom it is provided. It is being rolled out across all HSC Trust areas. Through Self-Directed Support, individuals are allocated a Personal Budget, which they use to get a package of services that best suits their needs and personal preferences. The Personal Budget can be (1) taken as a Direct Payment and used by the individual to buy services themselves, (2) used to set up a Managed Budget that is held by the Trust but controlled by the individual, (3) used by the Trust to buy services on behalf of the individual, or (4) any combination of these options.</p> <p>Although applicable to everyone assessed as needing social care, the concept of Self Directed Support, with its aims to facilitate individual autonomy and empowerment, is particularly consistent with the ethos of the SBPP and the 'personhood' narrative that is widely referred to/ used in the dementia care field.</p> <p>Self Directed Support provides a mechanism through which the flexible, personalised short breaks trialled via the SBPP may be procured on behalf of or directly by people with dementia and their family carers (and indeed other families with comparable needs). There are a number of established organisations active in the short breaks arena from which services could be purchased, not least those involved in the SBPP who have invested in the dementia skills of their staff.</p> <p>Further analysis is needed to clarify the cost implications of making short breaks like those trialled in SBPP more widely available. The value of the Personal Budget offered by a Trust may be higher or lower than the actual fee required to pay for a particular service. In that the SBPP evaluation has demonstrated in some cases willingness to pay/ contribute to the costs of the services, this should not act as a barrier to exploring how they are replicated and scaled up.</p> <p>Further work is required to connect and explore how the mechanism of Self Directed Support can be used to embed short breaks provision.</p>

## 10. Next Steps

The sustainability plan in development by Deloitte for the DTNI programme as a whole, recognises that agreement on lessons learned/ what has worked well as above, is the first and necessary step in the sustainability planning process for SBPP. While these lessons have clearly focused on those living with dementia, they are widely applicable to families with comparable needs.

Thereafter the plan proposes a communications exercise to share lessons learned and benefits for both service users and stakeholders (underpinned by an intent to facilitate change in mainstream provision) and subsequently a workshop involving key decision makers (from the Department, HSCB, PHA and the Trusts).

It also recognises that there may be some follow-up support needed to assist Trusts to embed revised processes (e.g. on commissioning and Self Directed Support) and new short break services. The evaluation team would concur with the logic of all of these stages and has added detail where appropriate against each of the steps proposed by the DTNI Sustainability Plan in the table below.

Step	Detail	Responsibility
Step 1	Finalise evaluation and agree lessons learned / what has worked.	DTNI Project Board
Step 2	Communicate lessons learned from the evaluation of SBPP and intent to facilitate change in short breaks.	Department of Health (Chief Social Worker & DTNI Senior Responsible Officer)
Step 3	Convene workshop including senior decision makers from Department, Board / PHA and Trusts. This needs to debate the three recommendations above in relation to (1) how the more person-centred, flexible and responsive short-break provision demonstrated in the SBPP can be embedded/ integrated into to the new dementia care pathway and mainstream service model and the financial and service delivery implications of doing so; (2) what the key short break supports/ offer should be; and (3) what mechanisms can be deployed to support this mainstreaming – be that Self-Directed Support and /or new commissioning approaches.	Department of Health
Step 4	Agree follow-up support to assist Trusts in embedding revised approaches.	Department of Health / HSCB

In any transformation programme, seeking to achieve shared ambitions for long-term change, there will be **barriers to mainstreaming/ embedding**, and as such it is important to acknowledge these and put in place mitigating efforts. One barrier is **ensuring early diagnosis**, which is crucial as the first step in securing information, treatment and care, to support people living with dementia to live well and independently. Accessing short-break support to enable family carers to sustain their role is contingent on their family member having a diagnosis/ assessed needs. Therefore, continued focus on early diagnosis is key as proposed in the new dementia care pathway and service model. A second barrier is **skills**, in that some of the provider organisations highlighted the difficulty of being able to recruit trained staff at the pace at which there was demand from families/ service users. Therefore, continued investment is needed in workforce development – supporting foundations upon which to build have been put in place via the Dementia Learning and Development Framework, Dementia Champions Programme and other related work supported by DTNI.

Finally, it is important to highlight that there is a ‘short window’ to build on the momentum of what has been achieved in the pilot phase. There is currently a growing body of evidence that the SBPP has been highly valued by the key stakeholder/ beneficiary groups involved in the delivery and receipt of support. Allied to this there are **concerns about the imminent withdrawal of the support** and of the feasibility of transitioning any/some families onto other support arrangements – all underlining the impetus for the ‘next steps’ planning process outlined above.