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Evaluation of the

Dementia Enablement Pilot Project

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Life Changes Trust
Evaluation Report
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Creating better lives.

CONTENTS

FOREWORD

Sometimes adjustments to the home are vital for helping a family member continue in their caring role. In 2014–15, the Life Changes Trust ran an Individual Awards Pilot Scheme in Argyll & Bute and Edinburgh. This scheme offered £500 to individuals living with dementia or unpaid carers of people living with dementia. They could use the £500 for anything that a) mattered to them; b) would make their life better; c) they would be unable to do without the Award. Unsurprisingly, the majority of the Awards were used for making the home a better environment for families living with dementia. These covered everything from installing key–safes and improved lighting to replacing flooring and upgrading boilers. The changes improved safety, brought peace of mind, and were met with much appreciation from carers and their families.

This need for support in homes drove the Life Changes Trust to ask why this was not being provided through the usual statutory means, i.e. equipment and adaptations. It also raised a question about the timing of such support, that is; what could be done early on after diagnosis that would prevent a crisis?

It became clear that four matters created barriers to support: qualifying criteria being designed to meet critical need only; qualifying criteria being skewed in favour of physical disability and not taking account of neurological conditions to any great extent; 'red tape' which meant need could not be met quickly; and no or little budget for preventative work. These led to the Trust funding the Dementia Enablement Project in partnership with Care and Repair Scotland to see what benefit could be gained if these barriers were removed, particularly with Post Diagnostic Support in mind.

A useful definition of Post–diagnostic support (PDS) is: any helpful support given by the statutory sector or the wider community after a person receives a diagnosis of dementia. Just now, PDS is defined narrowly in line with a policy–driven offer made by the Scottish Government through Scotland's National Dementia Strategies. The promise made by the national government is that everyone newly diagnosed with dementia will receive at least one year's post–diagnostic support in line with Alzheimer Scotland's Five Pillars model. Currently, the promise and the reality are quite different in many areas across Scotland.

The Five Pillars model does not mention the home specifically. The Eight Pillars model mentions 'environment', which could mean the home. Regardless, it has long been recognised that adjustments to the home environment are often essential to keeping a person with dementia there for as long as possible – for example, see the 'Being Home' report (2017) published by the Life Changes Trust in partnership with the University of the West of Scotland.

The Dementia Enablement work carried out by Care and Repair should be seen as an important access point to PDS for those who may struggle to see beyond their four walls, literally, following a diagnosis of dementia. The customer–centred, home based approach often means they can gain access where statutory services cannot, and this should not be under–estimated.

The Dementia Enablement Project highlights the importance of Care and Repair and other housing colleagues in planning how PDS will be delivered on an ongoing basis in individual Integration Authorities. They have insights and experience that could easily be overlooked in local dementia delivery plans and should be round the table at all stages of planning and review of delivery. What's more, it would be fruitful to fund them to deliver this specific element of PDS that can lead to a wider offer of PDS to the individual.

The experience and insight gained from piloting the Dementia Enablement Programme have shown us that people with dementia need multiple points of access to PDS and at various stages in their dementia journey.

We hope that by sharing the insights gained through this evaluation of the Dementia Enablement Programme, projects of this nature will become embedded in Post–Diagnostic Support, and help a population of individuals affected by dementia live safe, independent and fulfilling lives at home for as long as they are able.

Anna Buchanan, CEO, Life Changes Trust

Robert Thomson, National Director, Care and Repair Scotland

1. Summary

Background

1.1 The pilot Dementia Enablement Project (DEP) aimed to help people living with dementia to stay in their own homes for as long as possible. It focused on enabling safe and independent living, allowing people to maintain their routines and connections to their local community and at the same time, reducing the risk of falls and accidents, which can lead to costly hospitalisation or residential care.

1.2 The DEP originated from a partnership between the Life Changes Trust and Care and Repair Scotland. The Life Changes Trust is committed to improving the quality of life, wellbeing, empowerment and inclusion of people living with dementia, unpaid carers and young people with care experience. Since the 1980s, Care and Repair Scotland has helped older people to improve the liveability of their homes, ensuring that they better suit their needs.

Pilot

1.3 The project funded Dementia Enablement Officers (DEOs) and a budget for enablement equipment to support people living with dementia and, where relevant, unpaid carers. The project operated in four areas: Aberdeen, Angus, Lochaber, and Lochalsh & Skye. The pilot started in February 2016 and ended in July 2019 in all areas except Lochalsh & Skye, where the project completed in January 2019.

1.4 In each area the service combined visits and safety assessments, the provision of enablement equipment, advice and help to access further support and care services, and ongoing contact after the main work was completed. A DEO carried out a safety check and assessed the home environment, found out about the lifestyle of the person living with dementia and reviewed their needs. Together they selected equipment, from a core set of enablement adaptations, which would help to reduce physical and sensory challenges and make the home safer. The discussions also considered additional elements of support that could be provided by Care and Repair or other local agencies that would further maintain their independence and enable them to live safely in their home environment.

Evaluation findings

1.5 The DEP supported 1,281 people and supplied 4,313 pieces of enablement equipment. The project delivery adapted in each area to meet local needs and take account of the level and type of PDS, the existing partnerships, the local setting and the variation in the offer of statutory service support. The evaluation of the project showed that the pilot project had a positive impact and delivered a range of outcomes for people living with dementia that helped them to continue to feel and be safe and independent in their own homes. The

enablement equipment installed as part of the core offering or accessed with funding or other agencies with the help of DEOs reduced the risk of falls, lessened confusion and the likelihood of night-time wandering, and enabled participants to oversee further adaptations to their home. Advice and signposting offered alongside practical services meant that people affected by dementia received additional benefits and funding to stay in their own homes and could access social work or occupational services that increased their sense of safety and well-being.

1.6 For unpaid carers the DEP supported their role and helped them to feel more able to maintain their independence. People living with dementia and local stakeholders, across all four areas, noted that the DEP is their "go-to" point. This was echoed by unpaid carers who described the DEOs as a listening ear and a trusted source of advice and support for them on various aspects of living with dementia, far beyond the equipment and adaptations that were the core function of the service. The DEP in all four areas became a key deliverer of post-diagnostic support.

Cost-effectiveness

1.7 Whilst the estimated cost savings from maintaining people living with dementia in their own homes for longer are potentially significant, the DEP was by its nature an early intervention and the high care costs of dementia on the wider statutory services will not be experienced for several years. Although short-term costs were not reduced, we considered what costs needed to be avoided to make the project cost neutral and we did this by looking at preventing the costs of residential care and emergency hospital admissions for people living with dementia.

1.8 The average cost of the DEP across the four pilot areas was £886.17 per person. The standard rate for residential nursing care in Scotland is £714.90 per week. To be cost neutral, the DEP would have to reduce the average amount of time spent in residential nursing care by nine days for each person supported by the DEP. When we looked at the cost of emergency hospital admissions (£4,516) amongst the 1,281 people supported by the DEP, to cover the costs of the project there would need to be 252 fewer emergency hospital admissions.

1.9 If we consider the lower future costs alongside the impact on the quality of life of those supported by the project, with clear examples of prevented or delayed need for care home or hospital admission, we view the DEP as a worthwhile investment.

Recommendations

1.10 Several key themes and considerations emerged from the evaluation prompting further discussion and shaping recommendations for how to take this type of support forward on a national level.

Recommendation 1: Work similar to the DEP should become a standard element of any PDS offer

1.11 Home is the primary place of security for people living with dementia. As they navigate an increasingly confusing landscape, having a place of familiarity and comfort is key to their well-being, independence and safety. The drive of the DEP was to keep people living with dementia in their homes for longer, and this aim should have a greater prominence and be a feature embedded in any PDS programme.

1.12 A key finding of the evaluation of the DEP was that having a practical purpose to engage with people living with dementia was an acceptable and appropriate gateway to establishing a relationship and enabling access to other appropriate services. Many people struggle with the policy-led emphasis of PDS and so this hands-on approach to enablement makes for a 'softer' entry point into dementia support.

Recommendation 2: National models of PDS should share a core offering but adapt to local needs and reflect and acknowledge existing partnerships and services

1.13 One of the cornerstones of the DEP's effectiveness was its commitment to flexible delivery attuned to the needs of the local area. The evaluation has shown that, although the four areas broadly followed the same delivery model, the service was adapted in each area to meet local needs and to account for the level and type of support being provided by Dementia Link workers, the existing and newly developed working partnerships, the local setting and the variation in the offer of statutory service support.

1.14 The acceptance and support of local variations in the delivery of DEP, and the resulting outcomes achieved by contrasting formats show that a programme embedding flexibility of approach built around a core offering is a successful formula for other national programmes or approaches.

Recommendation 3 – Consideration of a wider definition of PDS and a more diverse range of delivery organisations would provide more relevant and effective support

1.15 To provide effective PDS requires a broader and deeper understanding of the aspects of a person's life that are most important when they receive a diagnosis. The home is possibly the single most important aspect in the early days following a diagnosis and each point when the dementia progresses. The DEP highlights how an organisation with an established and respected reputation, local knowledge of the people and the area and expertise in supporting older people to remain at home can play an essential role in PDS. In each Integration Authority there should be more consideration of the role of a wider range of local organisations like Care and Repair, in shaping and delivering PDS.

Recommendation 4 – A programme designed to support people affected by dementia at any point in the care or support pathway should include key features of:

- Workers with a specialist knowledge of dementia

- Continuity of support from one point of contact
- Meaningful involvement of the person with dementia in discussion and decision-making
- Referral processes embedded into the project at the earliest point at which the person is ready to engage
- Investment of time to get to know the individual and what they need
- Ensuring the enablement equipment addresses physical and sensory needs of people living with dementia

Recommendation 5 – Integration Authorities should ensure that their leadership and staff teams make stronger connections between relevant policies when developing their local dementia strategies, policy and practice

1.16 The DEP demonstrates in a very practical way that small interventions, delivered at the right time and in the right way, are vital to avoiding crises and expensive health and social care responses. Yet Integration Authorities that have responsibility for equipment, adaptations and preventative support have not, to date, looked closely enough at the links between PDS, adjustments to the home and longer-term cost savings to the individual and the public purse.

2. Introduction

2.1 In May 2017, the Life Changes Trust commissioned Blake Stevenson to evaluate the pilot Dementia Enablement Project (DEP), which operated in Aberdeen, Angus, Lochaber, and Lochalsh & Skye.

2.2 This is our final report, which discusses the process and impact of the project over its three and a half years of delivery (February 2016 to July 2019). Our report is based on evaluation activities we have conducted as well as information and data collected by the four areas.

National context

2.3 Improving care and support for people living with dementia and those who care for them is a major priority for the Scottish Government. The most recent National Dementia Strategy for 2017–2020, focuses on improving the quality of care for people living with dementia and their families through action focused on diagnosis and post-diagnostic support (PDS)[1]. The strategy recognises the importance of taking a person-centred and flexible approach to providing support at all stages of a person's experience of dementia.

2.4 The Scottish Government provides a guarantee that each person diagnosed with dementia will receive a minimum of one year's post-diagnostic support from a named link worker who will work alongside the person and their family. Post-diagnostic support "enables the person and their family to understand and adjust to the diagnosis, connect better and navigate through services and plan for future care including anticipatory care planning".

2.5 The Dementia Strategy is also supported by the Age, Home and Community: A Strategy for Housing for Scotland's Older People: 2012-21,[2] which helps people to remain living safely and independently at home rather than being admitted to a hospital or care home through, among other activities, the provision of aids and adaptations. A key outcome of this strategy is for more people with dementia to be enabled to live well and safely at home or in a homely setting for as long as they and their family wish.

2.6 The importance of timely support after a diagnosis of dementia is widely recognised.[3] People living with dementia benefit from earlier diagnosis but the British Psychological

[1] https://www2.gov.scot/About/Performance/scotPerforms/NHSScotlandperformance/Dementia-LDP

[2] https://www.gov.scot/publications/age-home-community-strategy-housing-scotlands-older-people-2012-2021/ 'Age, Home and Community: a strategy for housing Scotland's older people 2012-2021'

[3] https://www.bps.org.uk/sites/bps.org.uk/files/Policy/Policy%20-%20Files/Evidence%20Briefing%20-%20The%20Importance%20of%20Timely%20Support%20After%20a%20Diagnosis%20of%20Dementia.pdf

Society reported that many people received very little, if any, post-diagnostic support and that diagnosis without adequate support may not be beneficial, and could be detrimental[4].

2.7 Under the Housing Scotland Act 2006, the provision of adaptations, aids and equipment must be delegated. This means that there are a number of statutory duties relating to the adaptation of a house that must be met by IJBs and HSCPs. Duties including assessing for an adaptation, planning and resourcing to undertake adaptations, funding, as well as powers and associated budgets delegated for the planning and delivery of advice and assistance to Housing Associations in relation to adaptations have been delegated to IJBs.

2.8 People living with advanced dementia symptoms can also be at great risk of frailty and falling. To address this risk, the Scottish Government published the Falls and Fracture Prevention Strategy for Scotland 2019-2024 in July 2019 for consultation.[5] The strategy has a specific focus on falls related to people with underlying long-term conditions such as dementia, and identifies 12 outcomes including building resilience at population level, early action, and targeting evidence-based and personalised support.

2.9 The Scottish Government's Guidance on the Provision of Equipment and Adaptations covers other major policies like Self-directed Support, which aims to give people living with dementia more choice and control over the care and support they receive to help them lead an independent life.[6] Self-directed support in Scotland is part of the mainstream of social care delivery, and encompasses what has historically been called direct payments but can include personal budgets and other forms of control and direction on how support is provided. It allows an individual more flexibility, choice and control over the support they receive, and promotes confidence and wellbeing for those with an assessed need.

2.10 The Scottish Government guidance also covers free personal and nursing care (FPNC), which is available for individuals over the age of 65 who require it, whether at home, in hospital or in a care home.[7] However, FPNC policy is related to the provision of social and nursing care, not the provision of equipment and adaptations. Therefore, only memory and safety devices which help individuals manage their own personal care needs are included (e.g. the use of personal reminder systems to allow individuals to manage their medicines, or the use of sound/movement alarms linked to light controls to guide people with dementia to the toilet and minimise the risks related to wandering at night).

[4] https://www.dementiaaction.org.uk/assets/0000/3825/Faculty_of_Psychologists.pdf
[5] https://www.gov.scot/publications/national-falls-fracture-prevention-strategy-scotland-2019-2024/
[6] https://www2.gov.scot/Topics/Health/Support-Social-Care/Support/Self-Directed-Support
[7] Scottish Government (2019) Free personal and nursing care: questions and answers.

Providing support to people living with dementia

2.11 The Five Pillar Model of Post-Diagnostic Support[8], developed by Alzheimer Scotland, aims to support individuals and their families to live well with dementia. It is based on the belief that self-management is possible with dementia, provided people living with dementia receive immediate post-diagnosis support. Maintaining a healthy lifestyle and well-being is fundamental to this approach. To achieve this, people living with dementia must understand the disease, keep socially connected, maintain relationships, build on their capabilities, remain physically and mentally well, and have a clear pathway to individualised services and support. The model emphasises the importance of ensuring that people living with dementia receive adequate support when coming to terms with the diagnosis, and have access to the information, knowledge and support structures that can allow them to make early decisions to influence their future care and experience of dementia for the better.

2.12 Dementia Link workers develop a person-centred support plan with each individual using the Five Pillar Model as a basis. The plan covers five areas of activity including planning for future decision-making, peer support, planning for future care, supporting community connections and understanding the illness and managing symptoms.

2.13 Despite the Scottish Government's guarantee of one year's PDS, many people living with dementia are not referred for PDS, or do not take up the offer. Government statistics show that 8,178 people were referred to dementia post-diagnostic support during 2016-17, which is 47% of people estimated to be newly diagnosed with dementia.[9]

2.14 The work of the Dementia Enablement Project complements and reinforces the Scottish Government's PDS policy, offering important support for people living with dementia and their unpaid carers by providing aids, adaptations, reassurance and advice.

Overview of Dementia Enablement Pilot Project

2.15 The DEP originated from a partnership between the Life Changes Trust and Care and Repair Scotland. The Life Changes Trust is committed to improving the quality of life, wellbeing, empowerment and inclusion of people living with dementia as well as care-experienced young. Since the 1980s, Care and Repair Scotland has helped older people to improve the liveability of their homes, ensuring that they better suit their needs. Both organisations share a person-centred approach and focus on individual empowerment.

2.16 The pilot DEP aimed to help people living with dementia to stay in their own homes for as long as possible. It focused on enabling safe and independent living, allowing people to maintain their routines and connections to their local community. At the same time, the

[8] https://www.alzscot.org/our-work/campaigning-for-change/current-campaigns/5-pillar-model-of-post-diagnostic-support

[9] https://www2.gov.scot/About/Performance/scotPerforms/NHSScotlandperformance/Dementia-LDP

project aimed to reduce the risk of falls and accidents, which can lead to costly hospitalisation or residential care.

2.17 As part of the DEP, dementia-trained Dementia Enablement Officers (DEOs) visited the homes of people living with dementia to carry out a 'home safety check'. This involved identifying any potential safety hazards and offering advice and equipment to address these. The officer also made suggestions for equipment and adaptations that could make it easier for the person with dementia to remain at home.

Evaluation aims and approach

2.18 The key evaluation objectives of the Dementia Enablement Pilot project were to:

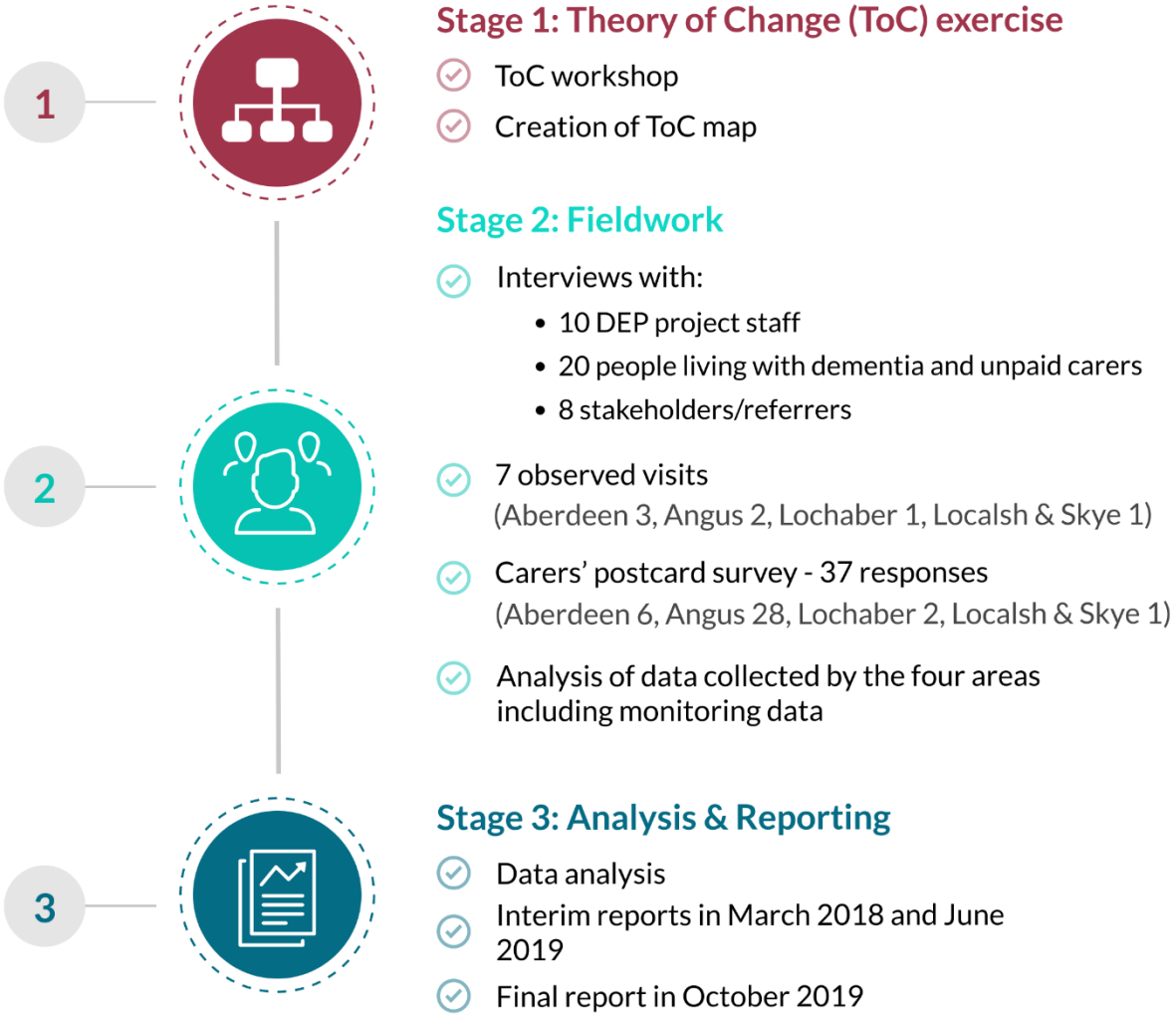
- assess and explain the project's impact on the lives of people living with dementia;
- gauge the extent to which the project has enabled people living with dementia to live safely in their home for longer;
- determine the extent to which the project has benefited the family and/or unpaid carers of people living with dementia;
- consider the cost-effectiveness of the project;
- analyse any potential geographical differences in relation to implementation, delivery and impact;
- assess and explain whether the project has had any wider impact on policy, practice and partnership-working, and how this has occurred; and
- provide recommendations on taking this approach forward on a national level.

2.19 The evaluation also aimed to provide insight into the appropriateness and usefulness of various adaptations which can then be shared with other stakeholders.

Methodology

2.20 The information and evidence gathered during the evaluation has involved visits to the four DEP areas, observation of the home safety assessment visits, interviews with people affected by dementia, unpaid carers, project staff and local stakeholders. We have also analysed data collected by the areas as part of the evaluation. Figure 2.1 summarises our methodology.

Figure 2.1: Methodology

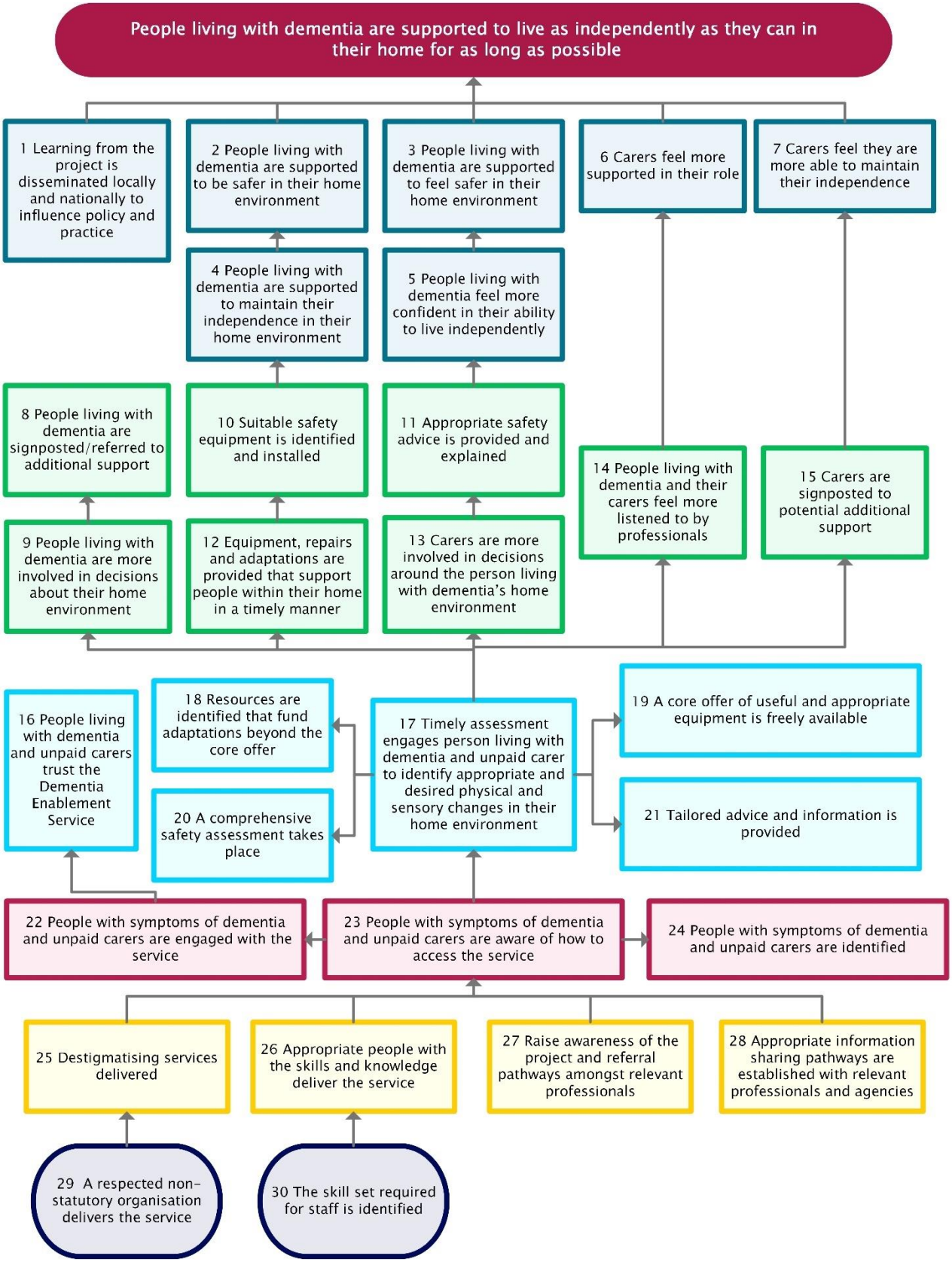


Framing the evaluation activity

2.21 The evaluation started by capturing what should be achieved through the delivery of the DEP. This was done by undertaking a Theory of Change (ToC) workshop to create a Change Map (Figure 2.2). The participants of this workshop included Life Changes Trust staff, the four Care and Repair services delivering the pilot, and other local partners and stakeholders including unpaid carers and health and social care workers.

2.22 The DEP Change Map visualised what the project was trying to achieve and what needed to change for it to work successfully. By identifying success criteria for a project, the map created a framework for evaluating the project. It helped to synthesise available evidence to understand the extent of success and how much of any success can be attributed to the project.

Figure 2.2: DEP Theory of Change Map



Structure of the report

2.23 This remainder of this report is structured as follows:

- Chapter 3 reflects on the key elements of the delivery of the DEP
- Chapter 4 explores the impact of the project
- Chapter 5 discusses points for consideration arising from the evaluation
- Chapter 6 contains recommendations based on the findings of the evaluation.

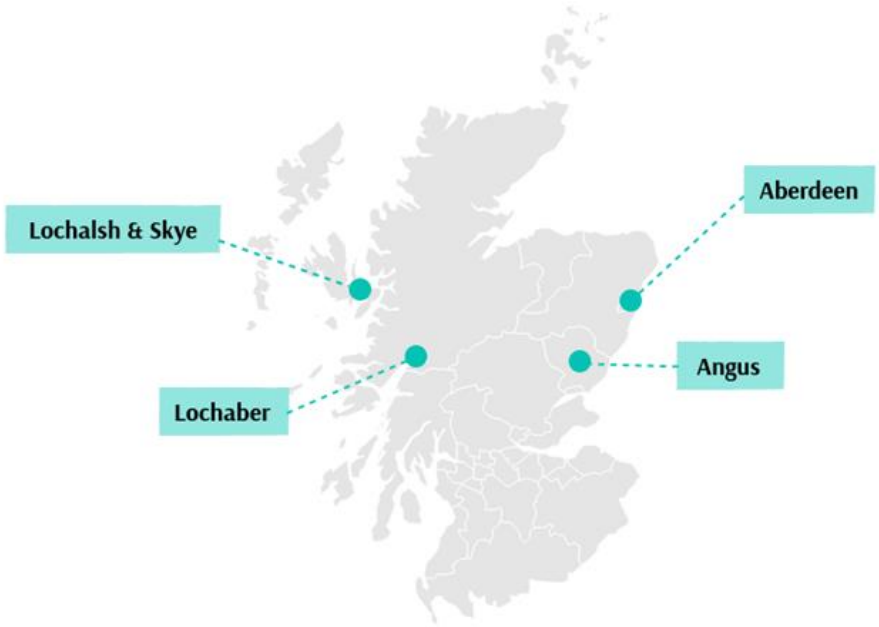
3. Delivery of the Dementia Enablement Project

3.1 In this chapter, we summarise the DEP's delivery model and present data about its operation over the three and a half years of the pilot.

The DEP

3.2 The project adopted a person-centred approach and funded Dementia Enablement Officers (DEOs) who worked with people living with dementia and, where relevant, their unpaid carers. Four local Care and Repair services delivered the pilot projects in their areas: Aberdeen, Angus, Lochaber, and Lochalsh & Skye. The pilot started in February 2016 and ended in July 2019 in all areas except Lochalsh & Skye, where the project completed in January 2019.

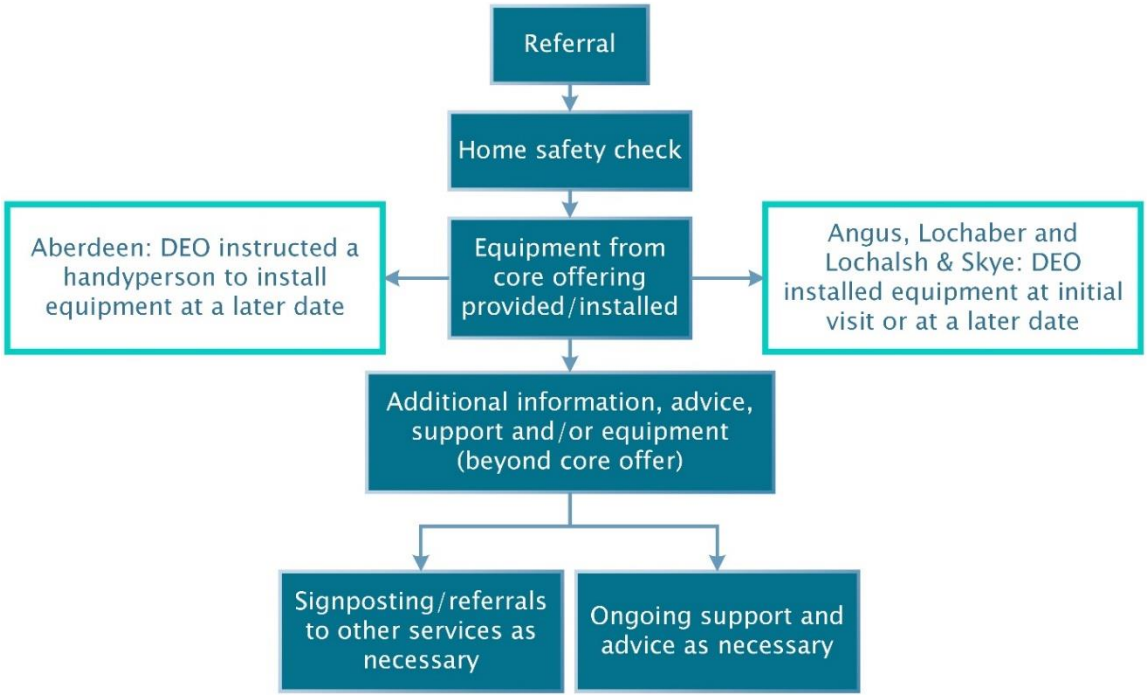
Figure 3.1: The four DEP areas



3.3 In each area the first visit followed a similar format. The DEO undertook a safety check and assessed the home environment, finding out about the lifestyle of the person living with dementia and reviewing their needs. Together they selected equipment, from a core set of enablement adaptations, which would help to reduce physical and sensory challenges and make the home safer. The discussions also considered additional elements of support that could be provided by Care and Repair or other local agencies that would further maintain their independence and enable them to live safely in their home environment.

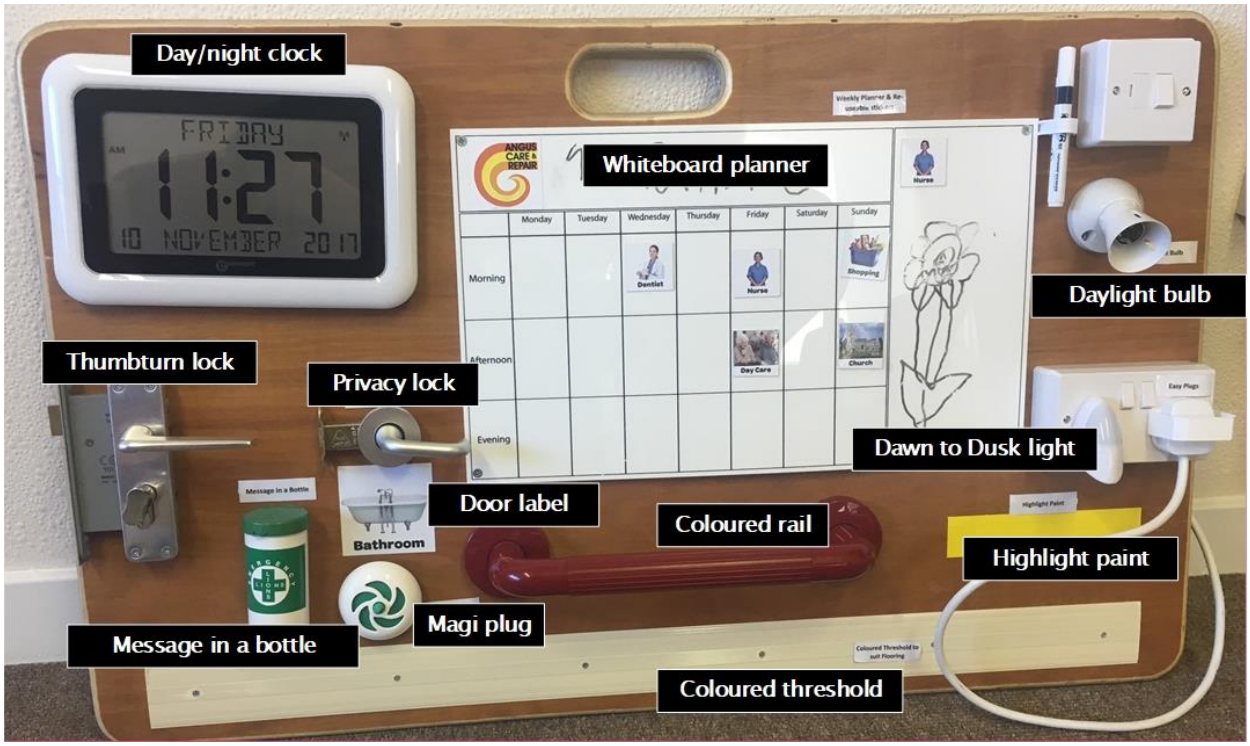
3.4 Figure 3.2 summarises the process for supporting clients.

Figure 3.2: DEP support pathway



3.5 The range of standard adaptations were fitted at no cost to the person living with dementia or the unpaid carer. The core offering of enablement items provided by the DEP is shown in Figure 3.3.

Figure 3.3: Core set of enablement adaptions



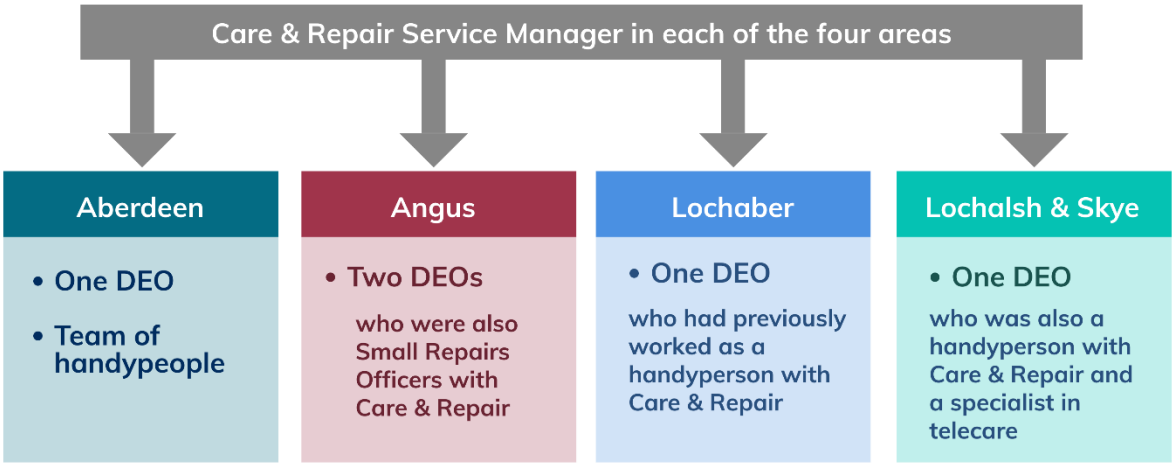
Local project delivery

3.6 In all four areas, the local Care and Repair service delivered the DEP followed a similar model but there were variations in some aspects of project delivery in each of the four areas. These are discussed below.

Staffing

3.7 Each area took a slightly different approach to staffing the DEP, as illustrated in Figure 3.4.

Figure 3.4: Staffing



Support provided

3.8 The core set of equipment was available in all four areas, along with some other services depending on local needs. Table 3.1 outlines the support provided in each area.

Table 3.1: Support provided in each area

	Aberdeen	Angus	Lochaber	Lochalsh & Skye
Core set of DEP equipment	✓	✓	✓	✓
Support/advocacy to access additional aids/adaptations	✓	✓	✓	✓
Signposting to other services	✓	✓	✓	✓
Support/advice with other issues e.g. applications for benefits and other financial assistance, Powers of Attorney and rent arrears	✓		✓	

Key partners

3.9 Each area developed partnerships with local organisations to assist and enhance delivery of the DEP. In Aberdeen, a pathway for minor aids and adaptations in owner-occupied properties was jointly agreed with Community Occupational Therapy, and this allowed the DEP to access additional pieces of equipment for those they supported.

3.10 In Angus, an agreement with Angus Council meant that Care and Repair staff could fit telecare and minor adaptations on behalf of the Health and Social Care Partnership (HSCP). In Lochaber, there was also an agreement with the HSCP which meant that where basic telecare had been installed, the DEO could install additional internal telecare equipment before formal approval had been received from HSCP staff.

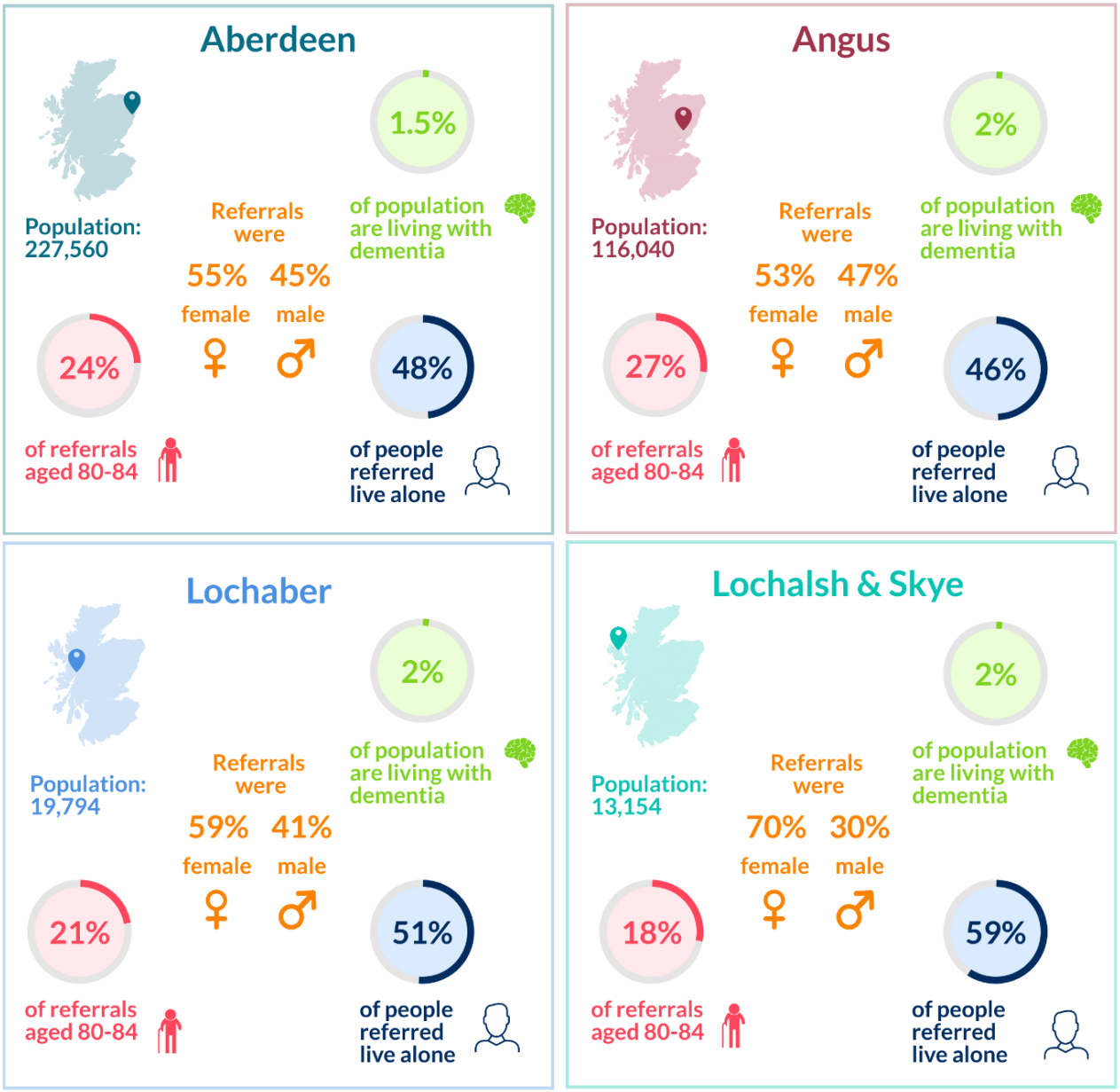
3.11 In Lochalsh & Skye they also had a good working relationship with HSCP staff. The DEO and other handypersons were trained as Occupational Therapy Assistants so they could carry out basic assessments and fit some equipment without involving the Occupational Therapy team. They hosted the community equipment store, carried out minor adaptations and telecare work for health and social care clients under a Service Level Agreement with Highland Council, and were able to install internal telecare equipment before formal approval was received from HSCP staff.

The DEP in numbers[10]

3.12 This section contains some key statistics about the DEP and the four areas of operation. Figure 3.5 provides an overview of the profile of the people supported in each DEP pilot area.

[10] Data about the size of the population in each area is taken from National Records of Scotland (www.nrscotland.gov.uk). The percentage of the population with dementia is taken from www.alzscot.org/campaigning/statistics. All other statistics are based on data collected by the four DEP project areas.

Figure 3.5: Area profiles



Number of referrals and cases taken forward

3.13 Overall, there were 1,315 referrals into the DEP, with the highest number received in Angus (557) and then Aberdeen (526). Lochaber had 150 referrals and Lochalsh & Skye had 82, these lower numbers were anticipated, given the smaller and more dispersed population in those areas.

Table 3.2: Number of referrals and cases taken forward

	Aberdeen	Angus	Lochaber	Lochalsh & Skye	Total
Number of referrals[11]	526	557	150	82	1,315
Number of cases taken forward[12]	504 (96%)	545 (98%)	150 (100%)	82 (100%)	1,281 (97%)

3.14 Table 3.2 shows that, overall, 97% of referred cases were taken forward; that is, the DEO spent some time on the case. There were 12 referrals in Angus and 22 in Aberdeen where the DEO did not record any time and whilst all the reasons for this are unclear, for some cases the advice was provided over the phone and for others circumstances changed quickly, for example, the person living with dementia moved to a care home.

Sources of referral

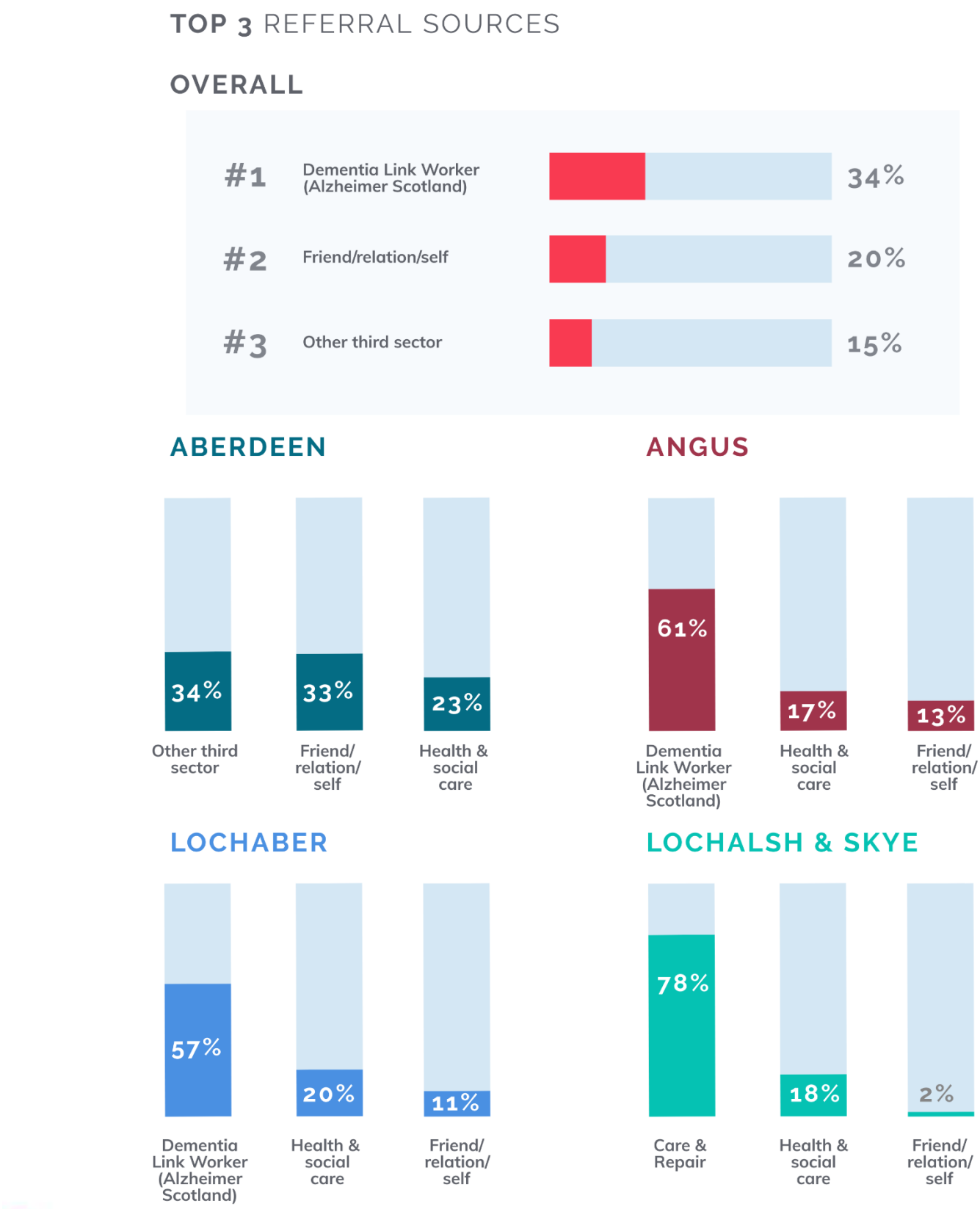
3.15 Across the four pilot project areas, there was some variation in the main sources of the referrals. In Angus and Lochaber, Dementia Link Workers (Alzheimer Scotland) accounted for the highest proportion of referrals to the DEP (338 (61%) in Angus and 85 (57%) in Lochaber). In Aberdeen, third sector agencies (excluding Dementia Link Workers) made the largest number of referrals (177, 34%) closely followed by people living with dementia themselves or their friends and family members (171, 33%). In Lochalsh & Skye, the largest number of referrals came from Care and Repair (64, 78%)).

3.16 Figure 3.6 summarises the referral sources at area and whole project level.

[11] Where referred people lived as part of a couple, the DEP's support benefitted both the person living with dementia and their partner/spouse. In our analysis, we have focused on the number of cases rather than the number of individuals involved. Therefore, we have counted cases where a couple was supported as one case (that is, one household), rather than two individuals.

[12] These figures include all cases where the DEO recorded at least some time against the case, even where the person subsequently died, moved or declined further support, and excludes anywhere there was no time recorded.

Figure 3.6: Top three sources of referral



Enablement items provided

3.17 The four areas provided data about the distribution of the enablement items from the core set. Across the project, 4,313 pieces of enablement equipment was provided. Angus distributed the largest number of items from the core offer (2,753, 64%), followed by Aberdeen (795, 18%), Lochaber (437, 10%) and Lochalsh & Skye (328, 8%).

3.18 Figure 3.7 shows that overall, the daylight bulb was the most common item supplied (1,502 or 35% of all items) and this was the most common item in each of the areas, except Aberdeen, where the day/night clock accounted for the largest number of distributed equipment (276, 35%). Further detail is contained in Appendix 1.

Figure 3.7: Equipment provided from the core offer

3.19 Some pieces of core equipment were more popular in certain areas. For example:

- in Angus 296 Message in a Bottle kits were supplied to clients but only one kit was distributed in Aberdeen, and none in Lochaber or Lochalsh & Skye;
- in Angus, 441 thumb-turn locks were fitted compared with 14 in the other areas combined; and,
- motion-sensor lights were more popular in Aberdeen where 117 were distributed, compared with three in Lochaber and none in the other two areas.

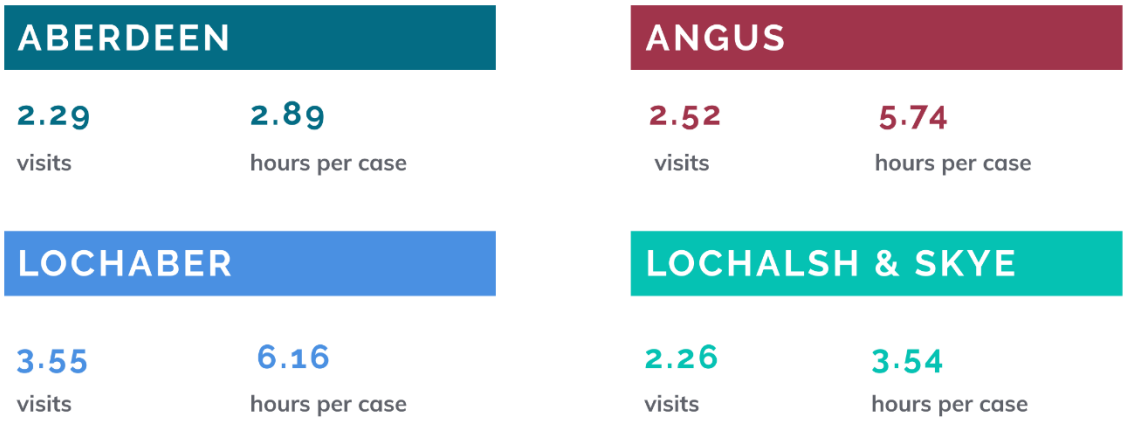
3.20 The analysis of the data reinforced the fact that people living with dementia were offered support beyond the core set of enablement items. There were 1,319 additional pieces of equipment distributed, with Angus accounting for most of these (77%). This equipment included grab rails, carbon monoxide detectors, smoke alarms, PIR lights as well as joinery, plumbing and electrical works.

3.21 The DEOs also provided support to 833 clients (63%) in the form of advice on financial entitlements, practical help with benefits applications, and signposting to other services such as respite care, social work, occupational therapy and other Care and Repair services.

The intensity of the support provided

3.22 There was variation among the areas in terms of the average number of visits and hours spent delivering support per case (Figure 3.8). Lochaber had the highest average number of visits per case (4) and the highest number of hours per case (6.16). Aberdeen had the lowest number of hours per case (2.89).

Figure 3.8: Average number of visits and hours per case



Cost of delivering the project

3.23 As part of the evaluation we considered the resource to deliver the project. The total expenditure and average cost per case is displayed in Table 3.3 and shows that the average cost per client in Aberdeen and Angus (£690 and £720 respectively) was more than 50% lower than in the pilot areas of Lochaber (£1,598) and Lochalsh & Skye (£1,892).

3.24 A DEO in urban areas can support more clients than one in rural areas, which may explain the difference in cost. In Lochaber the higher cost is due to the greater number of visits per client and longer time spent on each case than in other areas. However, the same is not true for Lochalsh and Skye, which had the fewest visits per client of any of the four areas. The difference in cost here could be due to the remoteness of some of the clients and associated travel time, which was not recorded as part of the project.

Table 3.3: Cost per client

	Aberdeen	Angus	Lochaber	Lochalsh & Skye	Total
Total expenditure	£347,647.83	£392,640.07	£239,748.35	£155,143.91	£1,135,180.16
Average cost per client[13]	£689.78	£720.44	£1,598.32	£1,892.00	£886.17

Current status of dementia enablement work in the pilot areas

3.25 The status of the DEP in each area, now that the pilot phase is finished, is summarised below:

- **Aberdeen**: The DEO's role continues until March 2020. Further funding may be available to continue the post for longer, but this is dependent on the results of the council-led review of post diagnostic support services in Aberdeen.

  As a result of the pilot project the DEP staff is represented on Aberdeen City's Health and Social Care Partnership's Integration and Housing Committee and the Independent Living and Specials Provision Strategic Working Group. They have also established a partnership working arrangement with the Occupational Therapists, who now supply and fit all modular handrails through their minor aids budget.

- **Angus:** Angus Council tendered the contract for Care and Repair services and Angus Care & Repair decided not to bid for this. As a result, the organisation ceased to operate at the end of July 2019, and therefore the DEP has not continued in this area.

- **Lochaber:** The DEP has been absorbed into the Care and Repair team and they will continue to carry out home safety checks, supply dementia-enablement equipment, and referrals will all be delivered by handy-people who have received appropriate

[13] The average has been calculated excluding the cases where no time had been recorded.

dementia training. Alzheimer Scotland in Lochaber now has a Communities Activities Organiser to help improve the physical and mental health of those living with dementia.

- **Lochalsh & Skye**: Funding from Life Changes Trust ended in January 2019 in Lochalsh & Skye. The DEP is not operating as a standalone project but core Care and Repair services are delivered in a dementia–friendly way.

Summary

3.26 In this chapter, we have described how the four pilot areas delivered the DEP in a similar way but elements of delivery were adapted in each area to suit local needs and the local population. We return to the issue of local variations in Chapter 5, and the next chapter contains a discussion about the impact of the DEP.

4. Impact of the Dementia Enablement Project

Introduction

4.1 Within the DEP Change Map (Figure 2.2), a series of outcomes were presented which visualised what the DEP was trying to achieve for people affected by dementia. We examined which of these outcomes were met based on the information from the interviews with people living with dementia; unpaid carers; project staff and referrers; observations; and qualitative client and carer feedback collected by the local areas.

4.2 This chapter includes a selection of case studies illustrating these outcomes. Some case studies focus on the impact of the DEP's core equipment and support, while others explore the impact of the wider support offered as part of the project. The names of case study individuals were changed to protect their anonymity.

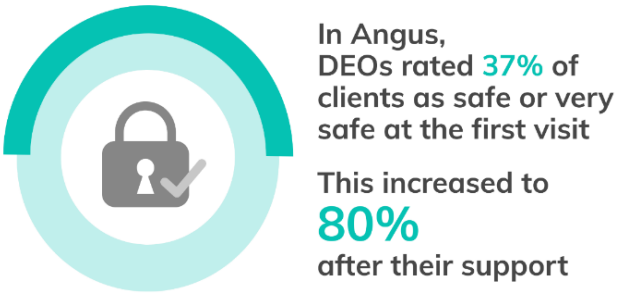
Impact on people living with dementia

4.3 There are several outcomes that the DEP should have delivered for people living with dementia. These focused on people with dementia **feeling** safer in their home environment, **being** safer in their home environment, supported to maintain their independence and feeling more confident in their ability to live independently. We discuss the DEP's impact in relation to these below.

People living with dementia are supported to be safer in their home environment

4.4 The DEOs, local stakeholders and carers provided evidence that the DEP was successful in helping people living with dementia to live in their own homes more safely. As one referrer said, the project "keeps them safe that bit longer".

4.5 In particular, unpaid carers of people living with dementia provided various examples of the DEP's equipment helping to reduce the risk of trips and falls. For instance, one noted that a motion–activated night light reduced the risk of her mum falling when she got up during the night and another commented that her husband was less likely to trip now that coloured threshold bars had been installed in the house.



4.6 In Trevor's story (Case Study 1), the DEP's equipment improved the lighting around his house, and the DEO believes that this prevented Trevor from having an accident.

Case Study 1: Trevor's story (Lochaber)

Trevor is in his mid 90s and has been diagnosed with Alzheimer's Disease

Trevor was referred by the Dementia Link Worker in April 2017 to ensure his home environment helped to maintain his independence and assist his carers.

Trevor is well-known in the community, having been a local shopkeeper for many years until his retirement. The DEO described him as bright and alert and fully aware he has the condition.

Timeline

Apr 2017

The DEO installed daylight bulbs, a clock and a whiteboard. Trevor had previously lost his keys and, although a local shop had volunteered to look after a spare key for him, a key safe was also installed.

Jul 2017

Trevor was happy with everything he had received on the first visit. He requested an additional daylight bulb above his chair. The DEO returned a few days later to fix the lock on his back door which was very stiff and difficult to use.

Oct 2017

Trevor asked for new lights in the kitchen as he couldn't see very well. The DEO replaced them and re-set them to cover the four areas of the kitchen. Trevor also asked the DEO to look at the outside light at the front door, which was old had corroded wiring. The DEO found the light was beyond repair, so he fitted both a light with a low energy bulb and a PIR sensor. Trevor was delighted with the work.

Jun 2018

The DEO undertook a follow-up visit and informed Trevor about The Life Changes Trust Individual Awards scheme, assisting him with completing the application form. He was successful with his application, and bought a new table and chairs.

Sept 2018

Trevor was asked if there was anything else the service could provide and he said "No – you have all been absolutely brilliant – I am so lucky".

Jun 2019

The DEO kept in touch with Trevor and witnessed a deterioration in his mental capacity. Trevor was admitted to the local hospital in June 2019 when his dementia became more severe and he became aggressive at times, which was out of character.

Trevor was to be discharged home. As part of his discharge, the DEO fitted Telecare, including sensors to the back and front door, a heat sensor and falls detector as well as smoke alarms. However, whilst in hospital his condition deteriorated and he was discharged to a care home.

Impact on Trevor

Trevor benefited from the core equipment which helped him to maintain independent living and may have prevented an accident as the lighting situation in his flat was vastly improved.

Everything supplied was met with genuine appreciation in that they made a difference to his life. In particular, he described the clock and whiteboard as "the best thing since sliced bread."

Case Study 2: Isobel's story (Lochaber)

Isobel is 72 years old and has Alzheimer's Disease

When she was referred to the Dementia Enablement project in 2016, she was living with her husband, William, who was also showing signs of dementia, but did not have a formal diagnosis.

Isobel was referred by the Technical Officer as he had been supporting the client and her husband with repairs to the property which they owned and thought that they would benefit from a Home Safety Check and also some specific dementia support.

Timeline

Jul 2016

The DEO carried out a Home Safety Check and supplied a Dementia Clock and a weekly planner whiteboard. He also fitted an internal banister and some grab rails which helped the client to balance.

He replaced the front door lock and also fitted a key safe to the property for the use of the carers and made a referral to Care & Repair for the fitting of an external galvanised rail.

Dec 2016

The DEO visited to check the galvanised rails had been fitted and that Isobel was managing to use them safely. The rails had been fitted and Isobel advised that they were a "godsend". She also asked if the lighting at her back door could be improved in any way so a quotation to install a new light was obtained from Lochaber 365. The DEO also fitted a lock-off on the microwave.

Feb 2017

The DEO returned as the lock-off on the microwave had been broken which he replaced.

May 2017

Isobel's daughter, Lisa, advised the DEO that Isobel's memory was deteriorating and that she was prone to leaving the cooker on and walking away from it. The DEO visited and fitted a lock-off on the cooker.

Jun 2017

Following a referral from Health & Social Care, the DEO installed Telecare, comprising of 2 smoke detectors, a heat sensor, My Amie pendant and a Lifeline Vi. The DEO returned a few days later following a referral from the Memory Nurse, to fit lock-off toaster sockets.

Jul 17-Feb 18

Following a call from the Night Owls Caring Service, the DEO carried out repairs to the lock-off on the microwave. All the kitchen electrical goods now had lock-offs to prevent either of the couple from cooking.

The DEO made several visits to the house in order to repair the lock-offs which were being broken on a regular basis.

Mar 2018

A fire broke out at the property and, as the Telecare smoke alarms alerted the Hub, the fire brigade responded.

Isobel and William were both placed into care homes over 100 miles apart. Isobel remains in long-term care and William has subsequently passed away.

Impact on Isobel

The DEO carried out 19 visits and fitted various items of equipment including telecare which ultimately contributed to saving their lives.

The deterioration in the health of both Isobel and William meant that various interventions and adaptations were made over a relatively short period of time. The interventions did help the couple to remain living in their home for longer, however, it was challenging for the family that both Isobel and William had dementia at the same time.

4.7 Local stakeholders recognised and appreciated how the enablement equipment helped to increase the safety of people within their own homes. For example, a professional noted that the behaviour of one of her clients was positively affected by the use of the clock. It had helped him determine whether it was day or night, reducing confusion and had possibly minimised the number of times he went out of the house after dark.

4.8 Similarly, the home safety assessment and the advice the DEOs provided enhanced the person's safety, even if no equipment was offered. The DEOs gave advice on simple changes that could improve home safety like removing scatter rugs, improving lighting in hallways and landings, rearranging plugs in multiway sockets to reduce the risk of electrical fires, and ensuring all smoke detectors were working.

4.9 In all areas the DEO supported people to access additional equipment that enhanced their safety in the home. In one area the DEO helped a person to source and install new carpets to make their floor less slippery. As can be seen in Isobel's story (Case Study 2), the DEO helped her to obtain telecare smoke alarms that were crucial when a fire broke out in their home.

4.10 As well as providing equipment and adaptations, interviewees described the importance of the DEO in signposting or referring people living with dementia to other services that helped to enhance their safety at home. For instance, the DEOs often referred people to agencies that provided community alarms, or to statutory services such as social work. In one case, the DEO's referral to an Occupational Therapist resulted in a mat and step to help the person living with dementia to use the shower more safely.

4.11 In Margaret 's story (Case Study 3), we describe how the DEO helped her to access various aids that made her safer at home.

Case Study 3: Margaret's story (Lochaber)

Margaret is 85 and has recently been diagnosed with a combination of Alzheimers and Vascular Dementia

Margaret lives alone on the upstairs level of a four-in-a-block flat. Her primary carer is her daughter, Sarah, who is married and works full-time.

Margaret was referred by the Dementia Link Worker to ensure her home environment helped to maintain her independence and assist her carers.

Lochaber Care & Repair had already carried out various adaptations and repairs at Margaret's house prior to her referral, including a level access shower and works to improve access to the property.

Timeline

Oct 2016

The DEO carried out a Home Safety Check, and Margaret welcomed suggestions to improve her safety. A Dementia clock and whiteboard planner were installed, making it easier for Margaret to keep track of her meals and any visitor appointments. A new banister and rail were also fitted.

Sept 2017

Margaret's daughter Sarah contacted the Dementia service as she was concerned that Margaret's condition had deteriorated. A few days later, the DEO visited and suggested that they consider having a stair lift installed as Margaret was struggling with climbing the stairs.
The DEO also suggested having a fall sensor connected, as Margaret had fallen recently.

During the visit, the DEO noticed that the grab rail at the front door had become rusty and returned to replace this a few days later.

Nov 2017

The DEO carried out a follow-up visit to change some bulbs to daylight bulbs and checked Margaret's Telecare system, at which time he also fitted the fall sensor.

The DEO returned a few days later to talk to the family about making a referral to OT for an assessment and they agreed that the DEO should proceed.

Mar 2018

The DEO observed that Margaret's mobility problems had deteriorate d. He checked on the progress of the stair lift installation and confirmed it would be fitted in May 2018. The DEO fitted 3 new grab rails in the hall and fixed the wooden handrail at the top of the stairs.

Nov 2018

Margaret requested a visit to repair an electric heater and fit new brackets in the bathroom. The DEO also fitted a new grab rail next to the toilet so Margaret could lower and raise herself off the toilet safely.
Margaret had recently fallen out of bed, so the DEO installed a second bed lever.

Jan 2019

Margaret requested another visit as she was having problems with the electric heaters in her bedroom and her new table was very unstable. The DEO was able to fix the table, however, as the the heaters were very old and the thermostats were not working, he was unable to repair them. He also concluded that the heaters posed a risk to Margaret, as she could easily burn herself on them. He recommended that Sarah purchase new panel heaters.

He returned a few weeks later to install the new panel heaters, and did a follow up visit later to ensure they were working correctly.

Impact on Margaret

The practical support and advice offered by Care and Repair has enabled Margaret to remain living in her home safely and provided peace of mind to Sarah.

Sarah reported that Margaret has developed a trust in the DEO and always recognises him even although she cannot remember his name.

Without Care and Repair's services, Margaret would probably have had to either relocate to a care home, or live with her daughter.

Case Study 4: John's story (Lochaber)

John was 69 when he was referred to the Dementia Enablement Project.

John lived with his wife, Mary, in the family home which he built himself when he was younger.

He had been diagnosed with Vascular Dementia, and suffered from other health problems, including visual perception difficulties, heart failure and mobility issues.

He was referred to the Dementia Enablement project as part of the one year post-diagnostic support offer.

Timeline

July 2016

The DEO visited and a Home Safety Check was carried out. The DEO supplied a Dementia clock and fitted an internal banister. He also repaired a broken lock on the bathroom door and fitted a grab rail in the shower. The couple were financially independent and John was in receipt of Attendance allowance. A further benefits check was declined.

The banister on the stairs had been handmade by John, but it was short at the bottom of the stairs. In order to maintain familiarity and continuity, rather than replace the existing bannister as standard, a bespoke piece of railing was made which matched the existing banister.

June 2017

Mary phoned to ask if grab rails could be fitted in the downstairs toilet as John's condition was worsening and he was struggling to get off the toilet, which was causing him distress.

When the DEO visited, he found that the fixings for the rails would not be secure and would also be in an awkward position. He fitted a toilet frame as an alternative, and John seemed pleased with this.

Sept 2017

The DEO carried out a review visit. Although John had been using the toilet frame successfully to assist him, he had taken a sudden dislike to it. Mary requested again that grab rails be fitted. The DEO explained that this would not be a safe option and suggested trialing another type of toilet frame. The DEO returned and replaced the toilet frame which John was happy to use.

Sept-Dec 2017

John had been periodically going to a local Residential Home to give Mary respite. His condition was deteriorating, but he was still fairly active and liked to walk daily. The DEO suggested a GPS tracker but this was declined as he was not inclined to wander on his own.

Dec 2017

The DEO visited to fit a bed sensor. The time lapse for the alarm was to be set for 20 minutes, but Mary asked him to change this to 1 minute. John had been getting out of bed to go to the toilet and as he now needed guidance to take him the toilet, he was relieving himself wherever. Changing the time lapse reduced the number of "accidents" significantly.

March 2018

During a period of respite at the residential home for a few days, John had an episode and was transferred to a psychiatric hospital for assessment. He subsequently returned home and passed away in the home he had built, with Mary in attendance.

Impact on John

The work and support provided by the DEO enabled John to maintain dignity, helped him to live in the house he had built, provided sensitive adaptations and provided solutions which helped John and Mary.

Over the period that the DEO worked with the couple, John's mental health deteriorated significantly and at a greater rate than his physical strength. Interventions delivered at the right time and as soon as they were needed, for example, the bed sensor, made a huge difference to not only the person but the carer as well.

John was able to remain and ultimately pass away in his own home, which was of great comfort to his wife and family. Had the DEO not become involved it is likely this would not have been the case.

4.12 The feedback from unpaid carers showed that the DEP supported people living with dementia to feel safer in their home environment. In Sally's story (Case Study 7) the equipment included a motion–activated light and support to obtain a stair lift and level access shower, which the DEO reported made them "both feel safe and secure".

4.13 The equipment that helped to ensure access to and egress from the home was welcomed. Some unpaid carers explained that the thumb–turn locks gave them reassurance that if there was a fire that everyone in the home would be able to get out safely. The installation of the keysafe was also reassuring for some, as one person living with dementia described, "[I] have peace of mind knowing that if I'm at home on my own and can't get to the door the keysafe is there to be of use".

People living with dementia are supported to maintain their independence in their home environment for as long as possible

4.14 The way in which dementia progresses means that an individual's ability to undertake tasks and activities decreases over time, and this can affect their ability to live independently at home.

4.15 However, there were many examples of cases where the equipment provided as part of the DEP, supported people living with dementia to maintain independence at home. For example, an unpaid carer described how grab rails fitted in the toilet meant her husband could continue to use the toilet without help, and that a rail at the back door allowed him to continue taking the bins out, which had always been one of 'his' chores. In a further example, a DEO explained that a person they supported was provided with a rail to enable him to get out of bed without any help. In another case, a person living with dementia said that she used the weekly planner to record dates and times of her appointments so that she remembered to attend them.

4.16 Unpaid carers of people with dementia described how the support from the DEO made a difference to their home lives.

"Everything done has been such a great help especially looking to the future if my husband's dementia deteriorates with safety locks, handrails and all other aids".

"The help the DEP provided for our mother was huge. The staff were extremely helpful in allowing her to stay safe and independent in her own home".

4.17 As well as the equipment provided by the DEP, unpaid carers and people living with dementia spoke positively about the DEOs' willingness to carry out other works and alterations to help them maintain their independence.

4.18 As a referrer said, the project "makes sure they're supported in lots of different ways". There were many cases where the DEP has helped people living with dementia to access other sources of funding, to purchase various pieces of equipment, make home alterations and access services. For instance, in one case the DEO helped a client to secure funding to install a ramp and this has enabled him to get in and out of the house in his wheelchair more easily. Another unpaid carer of a person with dementia said the DEO helped them to access funds for a new boiler, which ensured that their home remained warm.

In Aberdeen, the DEO rated 24% of clients as having a good or very good quality of life at the first visit

This increased to 35% after their support

Financial impact in Aberdeen

The work of the DEO in Aberdeen supported 582 clients to complete successful benefit applications. This secured £727,464.40 of additional income for people living with dementia, an average of £1,249.94 per person. Given that the DEP cost of delivering the pilot in Aberdeen was £347,648, for every £1 invested in the DEP, £2.09 was gained for clients in benefits and other forms of financial assistance. There were many positive comments about the assistance with benefit applications:

"The DEO provides invaluable support in accessing financial entitlements and providing adaptations and minor repairs that improve home safety for people with dementia and their carers"

(stakeholder)

"[The service] is well respected. Their approach to undertaking the work helps to unlock issues and challenges in navigating other services and it is done in a timely manner, from referral to providing support and solutions"

(stakeholder)

"Benefits applied for helped us financially… someone from Care and Repair helped with new boiler and grant towards it"

(carer)

4.19 In Aberdeen, the DEO helped people living with dementia to apply for benefits, such as Attendance Allowance, which helped to ease their financial pressures. Mark's story (Case Study 8) describes how the DEO helped the family to access a financial grant to fund essential repairs to their roof, thereby ensuring their home remained habitable; and Edward (Case Study 6) received extensive support with benefits and other financial challenges to ensure he continued living at home.

4.20 Overall, while there is no counterfactual evidence available (that is, we do not know what would have happened if the DEO had not supported an individual), we have gathered anecdotal evidence from interviewees that shows the DEO's support helped people with dementia to live at home for longer than would have been the case had the DEO not been involved. However, several accounts and case studies such as Isobel's (Case Study 2), John's (Case Study 4) and Anne's (Case Study 5), demonstrate how the equipment and support helped them to remain at home for much longer.

People living with dementia feel more confident in their ability to live independently

4.21 The evaluation evidence identified that some people living with dementia felt more confident in their ability to live independently as a result of the equipment and support provided through the DEP. For example, in Lochaber, 90% of clients in year 3 reported that they felt more confident to live independently. In another area, an unpaid carer explained that "by making life easier for my husband, he feels more confident within himself" and in another case thumb–turn locks, a clock, weekly planner helped a person living with dementia more confident in navigating his home and in remembering about appointments and chores. By providing support to access benefits and to overcome other challenges related to living with dementia, the DEO helped Edward and his brother (Case Study 6) to deal with dementia more confidently. In Sally's case (Case Study 7), motion–activated lights helped both her and her partner feel more confident in her ability to get up by herself during the night.

4.22 In Aberdeen, the DEP developed a partnership with the Intermediate Rehabilitation Unit that helped people being discharged from hospital to return home. The unit has 19 flats and as part of the preparation for moving home, the unit uses the same equipment from the core offer to establish routines and strategies that people can then recreate at home. The interviewee from the unit identified several patients who, without the assistance of the equipment in their rehabilitation, would not have been discharged.

Case Study 5: Anne's story (Lochalsh & Skye)

Anne is in her mid-80s and has dementia

Anne is widowed and lives alone. She has a son, Gavin, who lives in Glasgow and a daughter, Marie, who lives in Inverness. She has recently moved to a new property, which is located 20 miles from her original family home.

Anne has a private carer who provides domestic care twice a week.

Timeline

May 2016

The DEO carried out a home safety check and identified some modifications required to help Anne maintain her independence.

The DEO supplied a weekly planner whiteboard, although this was not used much, and later, daylight bulbs.

Jun-Aug 2016

The Care and Repair team made the modifications in Anne's home and updated her son Gavin on their progress. The work included renewing hinges on kitchen cupboards, replacing handrails at the back door and lubricating windows that were stuck closed.

Gavin visited his mum and reported some concerns that Anne's neighbours had seen her leaving her home at night time. After a meeting with the Lead of Technology Enabled Care (TEC), Anne was selected for a trial of a new monitoring system, which meant Gavin could remotely view all of Anne's activity and ensure she was not leaving the house at night.

Dec 2016

Anne began switching off her Telecare base unit at night. To prevent this, the Care and Repair team boxed the plug so Anne could no longer access it. They made modifications so Anne could still access her television plug safely.

Feb 2017

Anne started to refuse to use her bath. After a discussion with Gavin, the DEO asked Anne's private carer if she would be willing to assist Anne to bathe with the use of a bath lift, as she had previously been trained to use this equipment. The DEO then approached an NHS Occupational Therapist with a proposal for a bath lift, who approved the idea. This arrangement was very successful and Anne was able to use the bath again, with the support of her carer.

Impact on Anne

The DEO supported Anne to stay in her own home by installing a new monitoring system so that Gavin could view Anne's activity and ensure she was safe.

The DEO also liaised with Anne's private carer and an NHS Occupational Therapist to arrange for a bath lift to be fitted, ensuring Anne could stay at home with the support of her carer.

The DEO said that without their intervention, Anne would have entered long-term care two years earlier.

Anne's family were extremely grateful for her to have had an extra two years of independent living.

Case Study 6: Edward's story (Aberdeen)

Edward was recently diagnosed with early onset dementia at the age of 55

Edward had a job in a practical trade, but had to give this up. The reduction in income caused Edward and his main carer, his brother Brian, some concerns around money. He had never been out of work before, so was not familiar with the benefits system. As a homeowner of working age, Edward has a mortgage and was in the middle of renovating his home.

Brian approached the Citizens Advice Bureau (CAB) for help. The CAB referred them to the DEP and, after an initial phone call, the DEO visited Edward's home to meet Brian and Edward and assess their needs.

As this case pre-dated 'Frank's Law', Edward was not eligible for support with personal care because he was under 65.

Timeline

Aug 2018

First Visit

Discussion covered the brothers' concerns around finances and the benefits system. The DEO helped them to complete application forms for PIP, ESA and Council Tax exemption.

"Edward seemed apprehensive at the start of the visit but he relaxed as the conversation progressed." (DEO)

Sept 2018

Regular contact with the DEO, two more visits and frequent phone calls.

The DEO helped Edward to apply for an Individual Award to fund the setting up of a Power of Attorney (PoA) for Brian.

DEO referred him to Occupational Therapy to access a hand rail for his very steep front steps.

Oct 2018

The PoA was in place and brothers liaising with bank over financial issues.

DEO made a referral to Aberdeen City Council's Benefits & Money Advice team for help with mortgage arrears and overdraft.

Jan-Feb 2019

The family reported that Edward was having issues with his short term memory. DEO suggested contacting care management/GP. Brian made an appointment, at which the GP reviewed and altered Edward's medication. This had a positive effect on Edward's memory.

The DEO visited Edward twice to complete DWP forms for PIP and ESA (documents had been lost from the initial application).

Mar 2019

PIP, ESA and Council Tax exemption were in place to value of £745 per month.

Apr-Jun 2019

The DEO helped Edward to apply for charitable funding to complete his home renovations. This funding has been received, and the DEO will close the case when Edward confirms the refurbishment is complete.

Impact on Edward

The DEO supported Edward to stay in his own home by making practical changes to make his home safer, including referral to Occupational Therapy to arrange the installation of an external handrail .

The DEO also supported Edward to apply for benefits, and referred him to Aberdeen City Council's Benefits & Money Advice team for help with financial issues that had arisen after he had to give up work, including mortgage arrears and an overdraft.

The DEO observed that Edward "seems happier" and that he and Brian are more informed about where to go for help if they need it. She said the brothers now "have the tools to manage dementia with confidence and less anxiety".

Brian agreed, commenting that the DEO has helped them "to deal with things one step at a time", has been invaluable in navigating the benefits system and, overall, has made the experience less stressful.

Impact on unpaid carers of people with dementia

4.23 The DEP Change Map also identified outcomes for unpaid carers, and we discuss the extent to which the project achieved these below.

Unpaid carers feel more supported and maintain their independence

4.24 Unpaid carers viewed the DEP as a crucial source of support in several ways. The equipment and adaptations provided by the DEP helped the person living with dementia to do more for themselves, and this lessened the support that was needed from the unpaid carer. One unpaid carer explained that the day/night clock helped the person living with dementia to keep track of the days and reduced the need to telephone the carer to ask what day of the week it was. Another unpaid carer said that they used the whiteboard to prompt her husband to carry out his morning routine of showering, shaving and dressing without any help from her.

4.25 This form of support reduced elements of the caring responsibilities and the knowledge that the support provided by the DEP meant the person living with dementia was safer at home provided "peace of mind" amongst some unpaid carers. As a practitioner said, it provides "a small opportunity for them to relax or step back" and an unpaid carer confirmed that "anything that helps" her husband to maintain his independence took some pressure off her. Another carer observed that the DEP's "help made our day a lot easier for my husband and myself".

4.26 Some stakeholders also reported that by increasing unpaid carers' peace of mind, this can reduce their feeling that the person with dementia might need long-term care and increase their confidence in the person staying at home for longer.

4.27 Several carers and professionals, across all four areas, told us that the DEP is unpaid carers' "go-to" point. This was echoed by the unpaid carers who described the DEOs as a listening ear and a trusted source of advice and support for them on various aspects of living with dementia, far beyond the equipment and adaptations that were the core function of the service. The unpaid carers of people with dementia also knew that, even if the DEP could not provide the support required the DEO would do their best to put them in touch with another service that could assist, thereby playing a key role in linking people to other post-diagnostic support. As one carer, said, this is "exactly what you want at a time of need" and another said that she had no knowledge of dementia or the support available before her mother's diagnosis, but the DEP helped her to identify and access various types of support.

4.28 This wide-ranging support that the DEP provided was highly appreciated by unpaid carers, and Mark and Laura's story, Case Study 8, describes the importance of the DEP's support in helping Laura to cope with her husband's dementia.

Case Study 7: Sally and Peter's story (Aberdeen)

Sally is 79 years old and was diagnosed with vascular dementia in early 2018

She lives with her partner, Peter, who cares for her on a full-time basis. They have been together for 27 years and still go out most days so "there is little time for them to be bored".

In May 2018, Sally's Occupational Therapist referred the couple to the DEP for help with applying for Attendance Allowance.

Timeline

Jun 2018

The DEO carried out a home safety assessment. This included advice to remove rugs and objects lying on the stairs, which Peter did immediately. The DEO offered to install a rail and motion-activated lights and the couple accepted these. Peter explained that the rail has been helpful for Sally as she has limited use of her right arm, and the lights help to make sure she can see where she is going if she gets up during the night.

Jul 2018

The DEO helped the couple to complete an application for Attendance Allowance. The application was successful and the couple was awarded £85.60 per week.

Sept 2018

The DEO visited Sally and Peter to see how they were doing. The DEO observed that Sally's mobility had decreased and she had had repeated falls and had been admitted to hospital. The DEO referred Sally to the Occupational Therapy team for assessment. The OTs assessed Sally as in need of a stair lift and a level access shower. The DEO arranged for these items to be installed by Care & Repair's handypersons. The DEO also offered respite care for Sally while the work was taking place, but the couple felt this was not necessary because the installation would be complete within a week. The DEO also helped Sally and Peter to successfully apply for an Individual Award to fund the setting up of a Power of Attorney.

Oct 18-Aug 19

The couple is enjoying the stair lift and level access shower and have recently got back in touch with the DEO to ask for advice on decorating their living room, which is to be self-funded. The DEO continues to offer advice over the telephone to help this couple deal with life with dementia.

Impact on Sally and Peter

The DEO supported Sally to stay in her own home by:

- Offering advice on home safety issues, such as the removal of rugs that could have been a trip hazard.
- Providing a rail and motion-activated lights to enhance home safety.
- Helping the couple to obtain a stair lift and level access shower, which the DEO says has made them "both feel safe and secure".

Peter described the DEO as "very professional" and said they "would have been struggling" without her help, particularly as Peter explained that the DEO was much more accessible and responsive than statutory support the couple had been receiving

Case Study 8: Mark and Laura's story (Aberdeen)

Mark is 63 and was diagnosed with dementia in 2014.

He had a professional job but had to stop working in 2011 when he began showing signs of memory loss and confusion. He also had to stop driving and he can no longer carry out chores around the house and garden independently.

Mark lives with his wife, Laura, and his adult son, James. Laura is Mark's main carer. She initially reduced her working hours to part-time when Mark was diagnosed but gave up work entirely in 2018 to care for him.

She now undertakes all household tasks and looks after the family's finances. She also provides Mark with the care he needs, including helping him to shower and making sure he eats and drinks.

The couple's Occupational Therapist referred them to the DEP for help.

Timeline

May 2019

The DEO carried out a home safety assessment. This highlighted the things that Mark can still do for himself, like making a cup of tea, but also emphasised his reliance on Laura. The DEO offered some equipment from the core DEP offering, including a whiteboard, but Laura declined, explaining that she had tried things like that unsuccessfully in the past

The DEO continues to remind her that these are available if she changes her mind.

Jun 2019

Mark and Laura have both retired now so finances are tight, but repairs to their roof are now needed due to water damage. The DEO told them about organisations that could give them grants to help pay for this, including a fund specifically for retired people from Mark's occupation. The couple was not previously aware of this.

The DEO helped the couple to obtain quotes from some trusted traders and printed funding application forms for Laura to fill in.

Jul 2019

Laura had started to fill in application forms for the grants, and the DEO answered her questions about the form. Laura said she felt bad about asking for the money but the DEO reassured her that the money is there to help people in their position.

The DEO confirmed she would add a supporting statement to the application and submit it on the couple's behalf.

Impact on Mark and Laura

The DEO is supporting Mark to stay in his own home by offering advice on home safety issues and offering practical equipment to make the house safer. The DEO also helped to identify and apply for sources of funding to pay for essential repairs to their roof, and provided practical and emotional support for Laura.

Laura reported that the DEO's support has been very helpful. The DEO has made them aware of sources of funding for their roof repairs that they would not otherwise have known about, thereby helping to ease their financial concerns.

She also commented on the importance of the DEO's support in providing emotional support. Laura said that "being able to lay off to her" and discuss her worries with the DEO has helped her to cope with her caring role. She also said that the DEO is "very easy to get on with" and Mark looks forward to her visits because he has "a bit of a laugh with her".

Impact on local organisations

4.29 In considering the effect that the DEP had on local organisations, referrers commented that the service complements their work to support people affected by dementia through various ways:

- The DEP worked closely with statutory services, including sharing the results of home safety assessment, where appropriate, to inform statutory services' assessments of the support needs of people with dementia;
- The DEP was a valuable service to refer people to;
- The DEP helped to increase some organisations' knowledge of aids and adaptations for people with dementia: "[the DEP] has given us a bit more awareness of what can be put in place to assist people at home".
- The DEP can act as an "early warning system" for others in identifying people in the community who need support with dementia, even before they become known to statutory or voluntary support services.
- If implementing relatively low-level adaptations through DEP did not make a positive difference for the person living with dementia, this provided valuable evidence for statutory services to allocate resource for more in-depth, intensive support for the person.

4.30 In addition, there is evidence that the DEP had an impact on policy and practice within Care and Repair organisations more widely. In one area, a focus on dementia has been embedded into Care and Repair's strategy, and five other Care and Repair services in the locality have mirrored elements of the DEP in their service. The skills and knowledge of staff has extended beyond their workplace and in one area the handyperson is involved with setting up a Men's Shed project and is encouraging it to be dementia friendly.

4.31 Taking part in the DEP also helped to enhance awareness and recognition of the role that Care and Repair can play in supporting dementia. For example, in Aberdeen, the organisation increased their influence in shaping decisions about dementia policy and practice and they are now involved in discussions about the future of post-diagnostic support in the city, "DEP has opened doors for us".

> *"If it hadn't been for this project then this handyperson wouldn't have had the confidence to work with people with dementia".* (Care and Repair manager)

Summary

4.32 The information and evidence gathered through the evaluation shows that the DEP pilot has addressed the expected outcomes detailed in the DEP Change Map and a positive impact on people living with dementia, particularly in terms of supporting them to live

more independently at home for longer than they might have been able to otherwise, and in supporting unpaid carers with their caring role. The project also provided important support for other local organisations that work with people affected by dementia and had a beneficial impact on policy and practice in Care and Repair organisations involved in delivering the project.

4.33 In the next chapter, we discuss the key considerations arising from the findings of this evaluation.

5. Discussion and considerations

5.1 This chapter looks at five key considerations arising from our evaluation. The DEP's role in PDS; the importance of local variations in any standard delivery model; how local partnerships supported the DEP to meet local needs; the cost effectiveness of the project; and what aspects of the DEP make it a successful element of PDS.

Consideration 1 – What was the DEP's role in post-diagnostic support?

5.2 The home is still the primary place of security for most people diagnosed with dementia. Dementia can make the home seem strange or unsafe. For the unpaid carer, the home may become a place of work and challenge rather than somewhere to relax or seek refuge from the wider world. Our evaluation of the DEP has shown that simple and timely adjustments in the home can make an enormous difference to feelings of safety and wellbeing. Engagement with the wider world, even if that world offers support, is unlikely when the firm foundation of the home as a sanctuary is lost.

5.3 A large proportion of people diagnosed with dementia seem to struggle to accept the initial policy-driven offer of one year's PDS. Others would like to take up the offer but there is no-one to deliver it in their area. One finding from this project was that DEOs could gain access and trust where others could not. By having a practical purpose for entering the house, the DEO could offer specific solutions and then refer people to wider support.

5.4 The approach, service and support provided as part of the DEP highlight how this could be a key part of robust PDS.

Consideration 2 – Why were local variations in the delivery model important?

5.5 Our evaluation has shown that the project adapted in each area to meet local needs and to account for the level and type of PDS and the existing partnerships, the local setting and the variation in the offer of statutory service support.

5.6 In Aberdeen, assistance to access welfare benefits and other forms of financial support was not provided by the Dementia Link Workers, so this was a key element of the support offered by the DEO. As a referrer said, the DEP is "plugging a crucial gap in the city". By undertaking this support during the initial visit, rather than referring on to another organisation and a different person, the DEO maximised their support and reduced the number of services that people living with dementia and unpaid carers needed to engage with and instead this support was provided by one person who they trusted.

5.7 In contrast, in Angus, where there was a more robust PDS offer, the project enhanced that support. Cases were referred soon after diagnosis meaning that installation of equipment was timely and helped to future proof aspects of the home. Angus supported the largest number of cases and provided the most pieces of equipment per supported person.

Consideration 3 – How did local partnership working support the DEP to best meet local needs?

5.8 All four areas worked with, and developed new, local partnerships to ensure their DEP was most effective in supporting people affected by dementia.

5.9 In Aberdeen, new partnership–working arrangements were established with health and social care, housing and the third sector. This included an agreement with Community Occupational Therapy for a pathway for minor aids and adaptations in owner–occupied properties. The DEP in Aberdeen also formed a good working relationship with the Intermediate Rehabilitation Unit where people stayed as part of the preparation for living back at home. The interviewee from the unit explained that they used the DEP enablement equipment (aids that they could not normally access) to establish routines that could be replicated in the home environment and that this was hugely beneficial to staff and patients ahead of their discharge from hospital.

5.10 In Lochaber, there was an agreement between health and social care and Care and Repair that allowed the team to install basic telecare equipment under a streamlined approval process. This meant that those people supported by the DEP received the equipment promptly and it removed the delays created during the assessment, approval and fitting process.

5.11 A similar agreement existed in Angus between Care and Repair and Angus Council, so again, the staff could install telecare and minor adaptations following the home safety assessment.

5.12 In both Angus and Lochaber the DEOs had a good working relationship with Dementia Link Workers which lead to timely referrals so that the DEP engaged with people living with dementia soon after diagnosis. This could maximise the impact of the full range of the enablement equipment on supporting the person living with dementia to live at home safely.

5.13 A distinctive element of Lochalsh & Skye Housing Association (LSHA), which delivered the DEP, was that all the handypersons (including the DEO) were trained as Occupational Therapy Assistants. This meant they could carry out basic assessments and fit some equipment. This reduced the workload and travel time to homes for the OT team, allowing them to concentrate on more complex cases and, for people supported by the DEP, it avoided a long wait for an appointment with an OT and they received the support from the same, familiar person, i.e. the DEO.

5.14 The project in Lochalsh & Skye was further enhanced by the close working relationships between health and social care staff in the area. Under a service level agreement with Highland Council and NHS Highland they hosted the community equipment store and carried out minor adaptations and telecare work for health and social care clients and had the authority to fit telecare aids and some other equipment including grab rails and banister rails. They also worked closely with the staff and new OTs and other professionals

(community and student nurses, care at home staff, physiotherapists and social workers) received training from the DEO/handyperson service as part of their induction.

Consideration 4 – How cost effective was this approach?

5.15 It makes financial sense to enable people living with dementia to live at home for as long as possible. This echoes a policy aim set out by the Scottish Government: "We must ensure that Scotland has the right housing and support for older and disabled people so that they can live safely and independently in their own homes for as long as possible".

5.16 The strategy[14] for housing for Scotland's older people says "Scotland's National Dementia Strategy notes that most people with dementia wish to remain living at home, and that 63.5% do so. This brings benefits for them and lower costs. The Dementia Strategy highlights the importance of preventative support in enabling them to avoid crises and the potential need for expensive hospital services". It also brings benefits and lower costs to wider statutory services.

5.17 Our evaluation looked at the average cost of the DEP across the four pilot areas (£886.17 per client) against some of the benefits achieved. Many of the benefits described in this report cannot be quantified or represented in monetary terms but show that the DEP had a significant impact on aspects that affect the quality of life, such as the confidence to live independently or feeling safe to live at home.

5.18 Whilst the estimated cost savings from maintaining people living with dementia in their own homes for longer are potentially significant, the DEP was by its nature an early intervention and the high care costs of dementia on the wider statutory services will not be experienced for several years. Our evaluation found evidence that the work of the DEP supported people living with dementia to live safely at home for longer therefore it should delay the time when a person living with dementia needed residential care and it most likely reduced emergency hospital admissions. However, it was not expected or possible to find a reduction, in the short term, of the publicly borne costs of supporting and caring for the people affected by dementia.

5.19 Although short-term costs were not reduced, it is useful to explore the future costs that could be avoided. Our evaluation considered what costs needed to be avoided to make the project cost neutral. To do this we looked at how effective the project would have to be at preventing the costs of residential care and emergency hospital admissions for people living with dementia.

5.20 The standard rate for residential nursing care in Scotland is £714.90 per week or £37,277 per year. This only represents the amount of publicly funded support for people living with dementia below the lower capital limit and not the true cost of care. We have taken this conservative estimate of the cost of residential nursing care for people living with dementia and calculated that to be cost neutral, across all four areas, the DEP would have to reduce

[14] 'Age, Home and Community: a strategy for housing for Scotland's older people 2012-2021'

the average amount of time spent in residential nursing care by nine days for each person living with dementia who was supported by the DEP. This amount of time varies when we consider the individual areas. In Angus, for every person living with dementia who was supported by the DEP, the amount of time spent in residential care needed to reduce by seven days to make the project cost neutral. In Angus this was eight days, in Lochaber 16 days and Lochalsh & Skye it was 19 days.

5.21 Alternatively, whilst an estimated cost of an emergency hospital admission related to dementia is not available in Scotland, in England in 2017/18 the cost of such an admission was £4,516. This means that the costs of the project in Aberdeen would be covered if, for the 504 people supported in Aberdeen, there were 77 fewer emergency admissions amongst those people living with dementia. Similarly, for Angus, the costs of the project would be covered if amongst the 545 people living with dementia there were 87 fewer emergency admissions. In Lochaber, the equivalent figure would be 54 fewer admissions and it would be 35 fewer admissions in Lochalsh & Skye. Among the 1,281 people supported across all four areas combined, this figure would be 252 fewer emergency hospital admissions to make the DEP cost neutral.

5.22 If we consider the lower future costs alongside the impact on the quality of life of those supported by the project, with clear examples of prevented or delayed need for care home or hospital admission, we view the DEP as a worthwhile investment.

Consideration 5 – what aspects of the DEP make it a successful form of PDS?

5.23 Interviewees identified several essential and important aspects of the DEP's service (captured in the Change Map) and these are discussed below.

Experienced and knowledgeable staff

5.24 The DEP employed DEOs who are trained, knowledgeable and experienced in working with people living with dementia and of the services available in the local area.

5.25 A referrer said that the DEOs "have become really skilled" at working with people with dementia and unpaid carers, and this was reflected in the feedback from clients and carers. One unpaid carer explained that many professionals who visit her and her husband "ignore the person that has dementia" but, in contrast, the DEO "speaks to him first".

> *"Made us feel like someone really cared about us"* (unpaid carer)
>
> *"Trustworthy… very obliging"* (unpaid carer)

A core offer

5.26 Initiated by the home safety assessment, the DEO offered a core set of enablement equipment, for free, that people living with dementia may not have been able to access, either because of its cost, a lack of awareness of its availability, or where to source it. Some

of these, such as grab rails, were useful for some people, regardless of whether or not they had dementia, but others, such as the clock and weekly planner, were designed to support the cognitive and physical needs of people living with dementia.

Bespoke package of support

5.27 In addition to the core offer of equipment, the DEP provided support to access other equipment and services, thereby helping to address a wide range of needs.

5.28 Interviewees described how the DEP promoted safety and independent living by providing a bespoke package of equipment, adaptations and further support where necessary, tailored to individual needs. The tailored approach is exemplified by John's story (Case Study 4).

5.29 Unpaid carers explained how the DEO facilitated links to other services and access to additional equipment and raised their awareness of other services available for people living with dementia and unpaid carers. This played an important role in enabling people to access additional post-diagnostic support.

5.30 Stakeholders reported that one of the strengths of the DEP was that it provided more wide-ranging support than statutory services because it went beyond considering the physical needs of people living with dementia and also took account of the wider social and environmental factors that affect the safety and wellbeing of those they supported.

People living with dementia and carers were involved in decisions

5.31 In line with a person-centred approach, the DEOs ensured that people affected with dementia were meaningfully engaged in discussions about their support. Interviewees said they appreciated the DEO taking the time to discuss what support they needed and involving them in decisions about which pieces of equipment and adaptations to receive and which organisations they could be referred on to.

Timely support that was well resourced

5.32 DEOs completed a thorough assessment of the person's needs, they took time to get to know them, discussed their home situation, built a trusting and friendly relationship, and identified the support they required. Home safety assessments took between one and three and a half hours, and those supported reported that they did not feel rushed in this time unlike their experiences of other services that were short on resources and time pressed.

5.33 From observing the home safety assessments, it was clear that people living with dementia and unpaid carers valued the time that the DEO spent with them and, having established that relationship, they would be comfortable to see the DEO again when he/she returned for subsequent visits.

5.34 The DEO made adaptations immediately or shortly after the initial home safety assessment, which was often a shorter timeframe than other services. One person living with dementia said that she had waited for several months for her landlord to install a grab rail, but the DEO provided this within half an hour of their first visit. Others gave examples of having to

wait for a long time to receive support and/or equipment from statutory services, and some stakeholders identified that it was far more efficient for them to refer people living with dementia to the DEP, because it reduced the strain on their resources and enabled their clients to receive the support and equipment they needed more quickly.

Early intervention and links made across policy areas

5.35 Stakeholders observed that the DEP was most effective when people were referred soon after they had received a dementia diagnosis or had started experiencing symptoms. The DEO provided important early support in these cases and because they took a holistic approach of housing needs, the support for the unpaid carer, access to social care and financial support they identified a range of issues that might affect a person's safety or independence before challenges emerged.

5.36 Some stakeholders viewed the DEP as an early warning system highlighting issues before they escalate, or a situation reaches crisis point. They also recognised that introducing the enablement equipment at the early stage of dementia, gave people "a chance to get used to the equipment before the dementia advances, even if they initially think 'I don't need this yet'".

A trusting, supportive, long-term relationship

5.37 Unpaid carers and people living with dementia reported that the DEP provided a trusted source of advice and support. A carer described the DEO as their "go-to person" whenever she needed any advice and stakeholders described the DEP as a project with the time and resources to build a trusting relationship with the person and provide a more personalised and holistic service, with follow-up visits and telephone calls as required. This on-going support was something that statutory services did not always have the time to deliver.

Impartial, flexible and non-intrusive support

5.38 Feedback from people living with dementia, unpaid carers and stakeholders highlighted the impartial role fulfilled by the DEO. They felt that as a project that sat outside the traditional health and social care system, it was a less intrusive and stigmatising service. The DEOs took a flexible non-judgemental approach and had the scope to go beyond their remit and work in partnership across agencies to best support people affected by dementia. The DEO was also sensitive to the stigma that surrounded dementia. In one area, to help engagement, the DEO's described their initial visit as a home safety check and their job title was 'Enablement Officer', with no use of the word dementia.

6. Recommendations

6.1 Based on the key themes and considerations that emerged from the evaluation and explored earlier in the report, we have identified key recommendations that can inform any current and future PDS initiative or programme.

Recommendation 1: Work similar to the Dementia Enablement Project should become a standard element of any PDS offer

6.2 As highlighted in this report, home is the primary place of security for people living with dementia. As they navigate an increasingly confusing landscape, having a place of familiarity and comfort is key to their well-being, independence and safety. The drive of the DEP was to keep people living with dementia in their homes for longer, and this aim should have a greater prominence and be a feature embedded in any PDS programme.

6.3 A key finding of the evaluation of the DEP was that having a practical purpose to engage with people living with dementia was an acceptable and appropriate gateway to establishing a relationship and enabling access to other appropriate services. Many people struggle with the policy-led emphasis of PDS and so this hands-on approach to enablement makes for a 'softer' entry point into dementia support.

Recommendation 2: National models of PDS should share a core offering but adapt to local needs and reflect and acknowledge existing partnerships and services

6.4 One of the cornerstones of the DEP's effectiveness was its commitment to flexible delivery attuned to the needs of the local area. The evaluation has shown that, although the four areas broadly followed the same delivery model, the service was adapted in each area to meet local needs and to account for the level and type of support being provided by Dementia Link workers, the existing and newly developed working partnerships, the local setting and the variation in the offer of statutory service support.

6.5 In addition, each area went beyond the core requirements of the pilot and broadened their offering depending on the needs of those living with dementia. Aberdeen provided a holistic service that looked at all the areas affected by a dementia diagnosis, from housing and benefits to occupational therapy and enablement services at home.

6.6 The acceptance and support of local variations in the delivery of DEP, and the resulting outcomes achieved by contrasting formats show that a programme embedding flexibility of approach built around a core offering is a successful formula for other national programmes or approaches.

Recommendation 3 – Consideration of a wider definition of PDS and a more diverse range of delivery organisations would provide more relevant and effective support

6.7 To provide effective PDS requires a broader and deeper understanding of the aspects of a person's life that are most important when they receive a diagnosis. The home is possibly

the single most important aspect in the early days following a diagnosis and each point when the dementia progresses. The DEP highlights how an organisation with an established and respected reputation, local knowledge of the people and the area and expertise in supporting older people to remain at home can play an essential role in PDS. In each Integration Authority there should be more consideration of the role of a wider range of local organisations like Care and Repair, in shaping and delivering PDS.

Recommendation 4 – A programme designed to support people affected by dementia at any point in the care or support pathway should include some key features.

6.8 There are many services that support people living with dementia and unpaid carers. Those supported by the DEP benefitted from the dementia–focused nature of the enablement equipment, the DEOs' experience and skills in working with people affected by dementia, time to carry out a comprehensive assessment of the person's needs and build up a trusting relationship. The combined features of the programme created a successful format, and these are:

- Workers with a specialist knowledge of dementia
- Continuity of support from one point of contact
- Meaningful involvement of the person with dementia in discussion and decision–making
- Referral processes embedded into the project at the earliest point at which the person is ready to engage
- Investment of time to get to know the individual and what they need
- Ensuring the enablement equipment addresses physical and sensory needs of people living with dementia

Recommendation 5 – Integration Authorities should ensure that their leadership and staff teams make stronger connections between relevant policies when developing their local dementia strategies and local policy and practice

6.9 The DEP demonstrates in a very practical way that small interventions, delivered at the right time and in the right way, are vital to avoiding crises and expensive health and social care responses. Yet Integration Authorities that have responsibility for equipment, adaptations and preventative support have not, to date, looked closely enough at the links between PDS, adjustments to the home and longer–term cost savings to the individual and the public purse.

APPENDIX 1: STATISTICS ABOUT THE DELIVERY OF THE DEP

Figure A1.1: Sources of referral

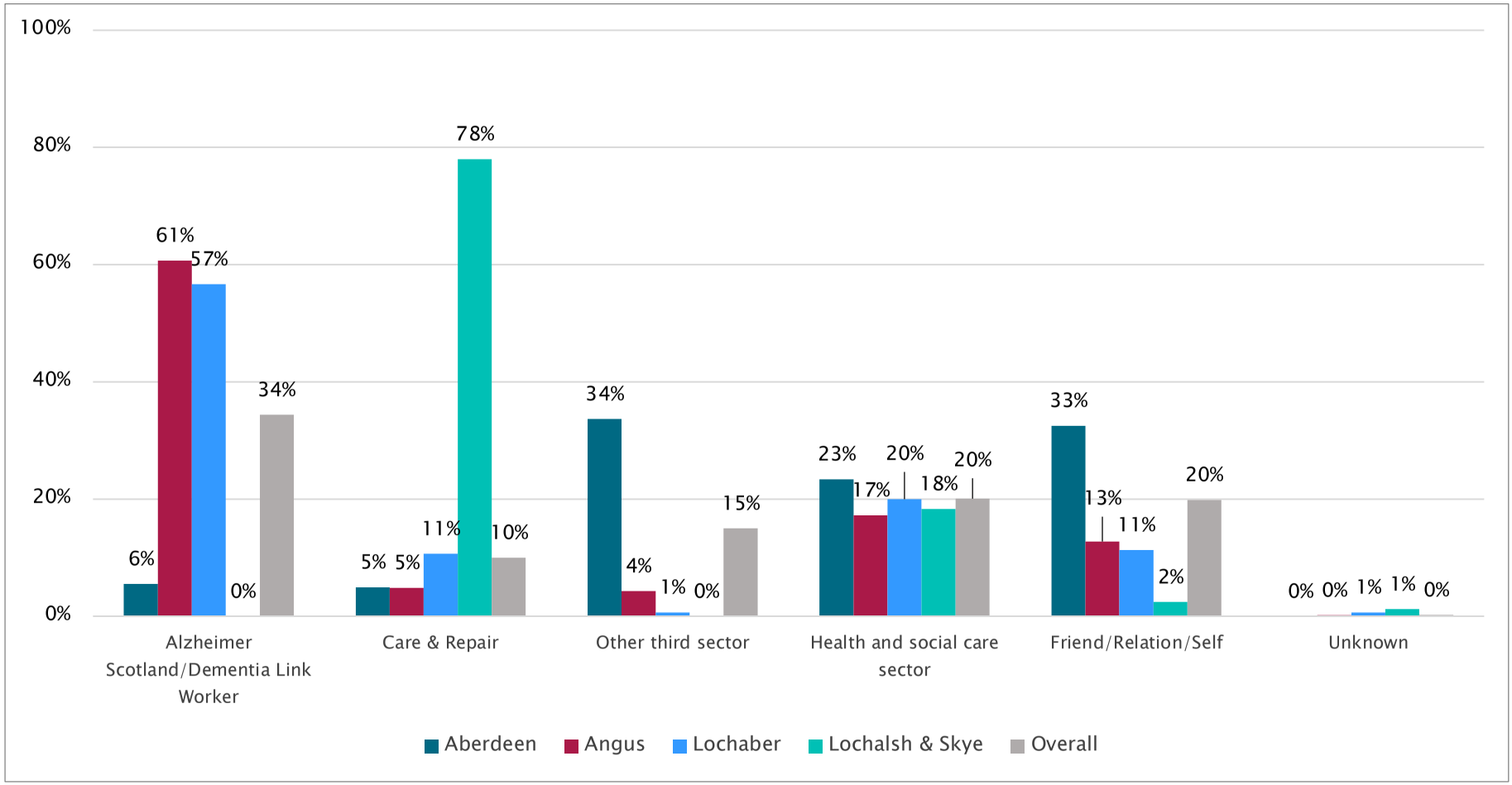


Figure A1.2: Items provided from the core offer