Personalised Psychosocial Supports and Care for People with Dementia in the Community

Investigation of the value case , May 2018

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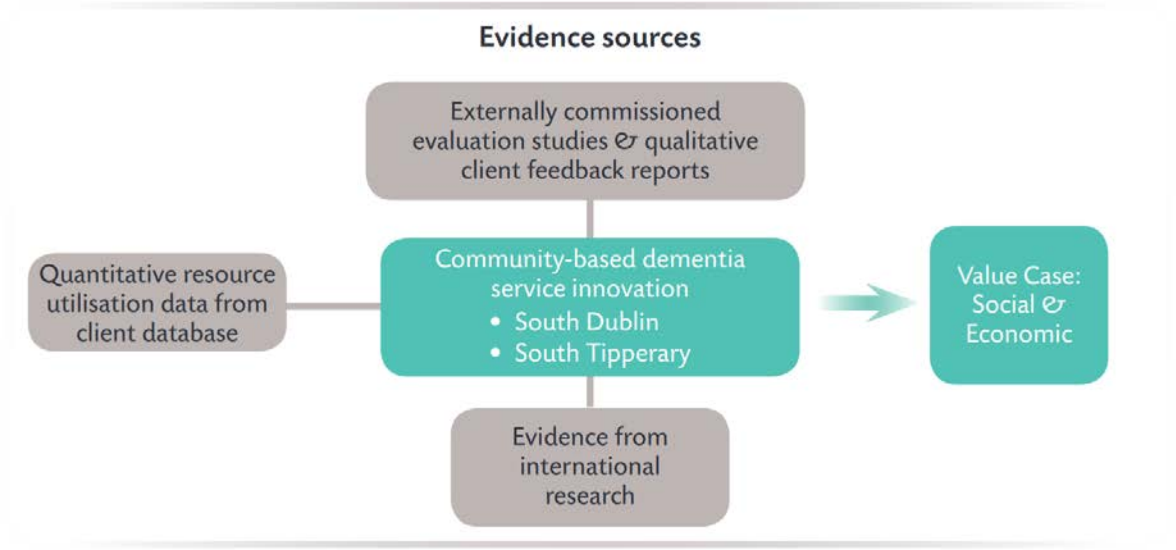
Executive Summary

It is widely acknowledged that community-based supports for people with dementia and their families have been underdeveloped in Ireland. The HSE & Genio Dementia Programme has been seeking to address this through an alignment of goals and funding from the Health Service Executive (HSE) and the Atlantic Philanthropies. The programme develops and tests new service models to transform the range and quality of community-based supports for people with dementia in Ireland, and to change how we think about supporting people with dementia and their families. This is in line with government policy, as expressed through the Irish National Dementia Strategy, which aims to support people to remain at home, living full lives for as long as possible, and supporting families and local communities in this goal.

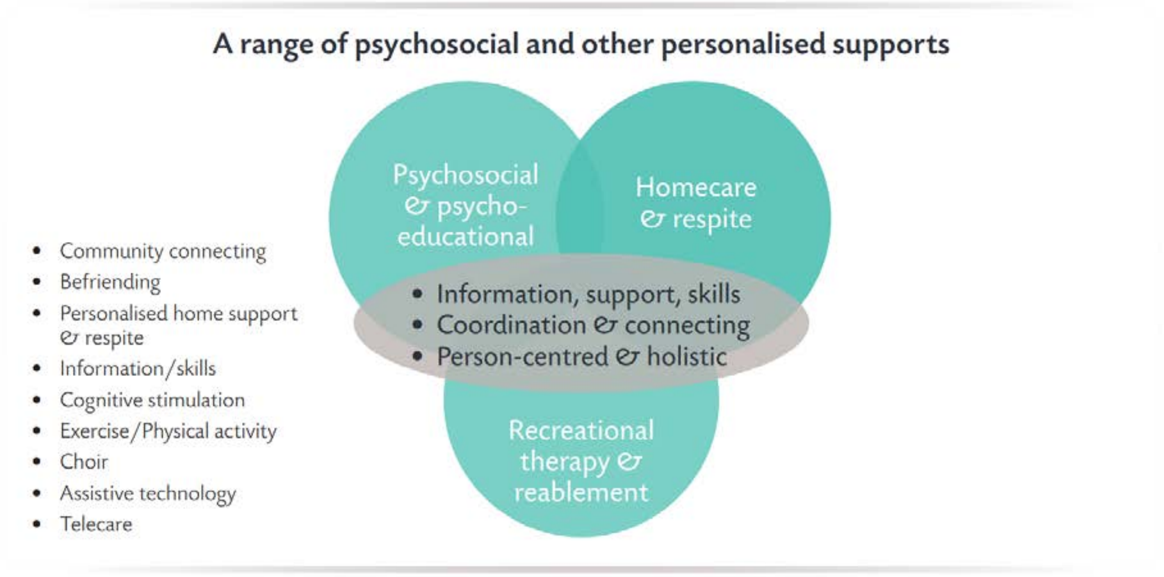
This Executive Summary presents a synopsis of the results from a study funded by Genio, with the support of the Atlantic Philanthropies, to assess the value case for these innovative community-based supports for people with dementia in Ireland. The study analysed Irish data and research evidence from the HSE & Genio Dementia Programme, and placed this in the context of the wider international research evidence.



It aimed to: (1) provide a synthesis and analysis of the social care value and value for money of a range of psychosocial and other personalised supports; and (2) examine the case for their incorporation into mainstream care for people with dementia across the country. These aims are linked to one of the key actions of the National Dementia Strategy - the provision of integrated services, care, and supports for people with dementia and their carers, informed by principles of personhood and citizenship.

Dementia Programme projects

The study focused on two substantial HSE-led demonstration projects funded under the HSE & Genio Dementia Programme, one in South Dublin (Stillorgan/Blackrock) and the other in South Tipperary. These projects were open to anyone with a diagnosis of dementia and so reflected 'real world' conditions. As a result, participants encompassed a broad range of people with dementia and carers in their types and severity of needs, ranging from people who were at an early stage with mild symptoms to a substantial number with more advanced dementia and higher risk of entry to long-stay residential care in the near-term.



The projects provided a diverse range of supports, with personalisation and the promotion of personhood at the core of all of the supports and services developed and delivered. The term personalised, as used by the projects, is a broad term that describes the different ways to support the person with dementia to maximise their abilities and to remain living as full a life as possible. The diverse range of personalised supports developed and provided by the projects makes it difficult to neatly categorise them. For purposes of this report, the term psychosocial support has been adopted as shorthand, but this encompasses a broad range of supports developed by the projects. It includes a variety of reablement supports on an individual or group basis, with a strong focus on connecting (or re-connecting) persons with dementia with activities in the community. Both projects also allocated substantial resources to personalised home supports, aiming to simultaneously provide respite for carers and positive, person-centred, benefits for persons with dementia.

Impacts for persons with dementia and family carers

Analysis of the extensive body of evaluation evidence from the projects found that the programmes of supports helped many persons with dementia and their family carers to live well with dementia. This included benefits for the person with dementia, for family carers, and at the wider family level. Each form of support proved useful for many people who used it. In addition, many people used a combination of the supports and gained substantial value from having the possibility to select from a variety of supports and receive tailored support packages designed to meet their preferences, circumstances, and needs. The results are congruent with the evidence from the wider international research literature indicating the value of psychosocial and other personalised supports, the importance of tailoring supports to relevant and achievable domains of gain, and the particular value from supports that target gain for both the person with dementia and family carer.

Some key areas of benefit for persons with dementia and their carers	
Person with Dementia	▪ enhanced personhood ▪ gains in subjective wellbeing ▪ enabled to live longer at home
Family Carers	▪ reduced burden and negative impacts on wellbeing ▪ enhancement of more rewarding aspects of caring ▪ reduction in opportunity costs of caring
Couples/Families	▪ relationship-related gains ▪ satisfaction from sustaining living at home

Resource allocation and value for money

Economic analysis and value for money analysis of data on support hours provided to each person shows a potential for substantial cost avoidance through prevention or delay of entry to nursing home care. The demonstrable quality of life and subjective wellbeing gains provide a crucial and essential component of the social gain and value-for-money case. In their own right, these gains for persons with dementia and family carers represent considerable value for the health and social care system, even before considering the potential long-stay residential care cost avoidance.

Resource allocation and value for money - key points

- Reflecting the personalised model and variety of psychosocial supports on offer, there was wide variation across service users in the mix of supports used, patterns of usage over time, and total number of hours used
- Overall, levels of project support were low, averaging between 1 to 2 hours per week per person; on an aggregate national basis, just a modest addition to the 'usual' social care allocation for older persons would enable widescale national roll-out of the approach
- According to an economic analysis by O'Shea and Monaghan (2016), the estimated potential cost avoidance for 181 people over a fifteen-month period is €3 million, using this approach.

From a national resource allocation perspective, a relatively small percentage increment in the standard allocation of social care supports for dementia care could enable provision of additional, personalised psychosocial supports for a large number of persons with dementia. Additional budgetary resourcing on its own will not necessarily lead to delivery of such supports to people with dementia, and the projects employed a local consortium model which was key to the success of the approach. This involved HSE-led coordination and funding, with implementation and delivery in association with a local consortium.

Conclusions

There is a demonstrated and compelling value case for provision of personalised psychosocial supports as part of care for people with dementia living in the community in Ireland. This is underpinned by an extensive range of evidence from the projects and from the wider research literature. The incremental costs, over and above standard care costs, are relatively small and represent good value for money in delivering on dementia policy and the National Dementia Strategy. In addition, there is the potential for substantial savings from delay or avoidance of long-stay residential care costs.

The evidence presented in this report indicates a strong case for resourcing the provision of personalised psychosocial supports across the trajectory of dementia, including the personalised supports of lower intensity demonstrated by these projects. These lower intensity supports could reach large numbers of people with dementia and family carers, particularly at an earlier stage, and could then be scaled and reconfigured to respond as individual need increases. The projects show that it is practically feasible to implement these types of services at local level within HSE community care services. The basic model could be replicated in every area across the country, whilst allowing for tailoring and fine-tuning to local needs and capacities.

1 Introduction

One of the core objectives of the Irish National Dementia Strategy concerns provision of integrated services, care, and supports for people with dementia and their carers (Department of Health, 2014). Internationally, best practice in dementia care recognises the importance of personalised and person-centred approaches that support living well with dementia for people with the condition and their family carers. Current publicly-funded, community-based, dementia care in Ireland is mainly through standard homecare services, with a gap in knowledge and evidence on the value and feasibility of incorporating a more person-centred dimension.

This report presents the results from a study funded under the HSE & Genio Dementia Programme. This Programme has developed incrementally since 2012. One of its main elements is community-based supports for people with dementia (HSE & Genio, 2016a). Within this element of the Programme, four projects around Ireland received funding and worked over three years to develop a range of community-based personalised supports for people with dementia in their geographical areas. A further five projects were funded to develop individualised supports for people who are at a more advanced stage of dementia and more complex needs (Genio, 2016a). Two of the original four projects, both HSE-led projects, took part in this study - *Living Well with Dem*entia in Stillorgan/Blackrock, and *5 Steps to Living Well with Dementia* in South Tipperary.

The report brings together and builds upon the research, evaluation, and learning from the first four projects funded under the HSE & Genio Dementia Programme. This includes evaluations of innovative respite (Cahill et al, 2014; 2014a) and assistive technology and telecare (Cullen et al. 2016), an economic analysis (O'Shea and Monaghan, 2016), and a community supports model for people with dementia developed through a service design process (Genio, 2016b). The report aims to build on this work by providing further analysis and synthesis exploring the nature of the innovative supports, and highlighting additional value to the person, family, and health and social care system, over and above the economic value.

This analysis is used to inform the case for mainstream provision within dementia care services across the country, as advocated in the service design blueprint developed from the programme's experiences. Alongside the analysis of the overall economic case for the innovative dementia projects, this will be a useful contribution for informing efforts to achieve the objectives of the Irish National Dementia Strategy on provision of integrated services, care, and supports for people with dementia and their carers.

1.1 Objectives

The overall aim of the study was to examine the case for public provision and funding of a range of innovative community-based supports as part of the mainstream approach to caring for people with dementia across the country.

The objectives were to:

- conduct an in-depth examination of the services/supports and outcomes for people with dementia from the HSE & Genio funded dementia projects in two of the sites (Stillorgan/Blackrock and South Tipperary)
- review available evidence from the wider research literature on the value of the main types of community-based services and supports provided by the projects
- prepare a synthesis and analysis of the social care value and value for money of personalised and person-centred supports, and examine the case for their incorporation into mainstream care for people with dementia across the country.

1.2 Methods

The study mainly involved secondary data analysis and literature review. This included analysis of quantitative data on service usage and qualitative data from the persons with dementia and their family carers supported by the projects, as well as evidence from the wider international research literature in this field (Figure 1.1).

Figure 1.1 Approach and data sources

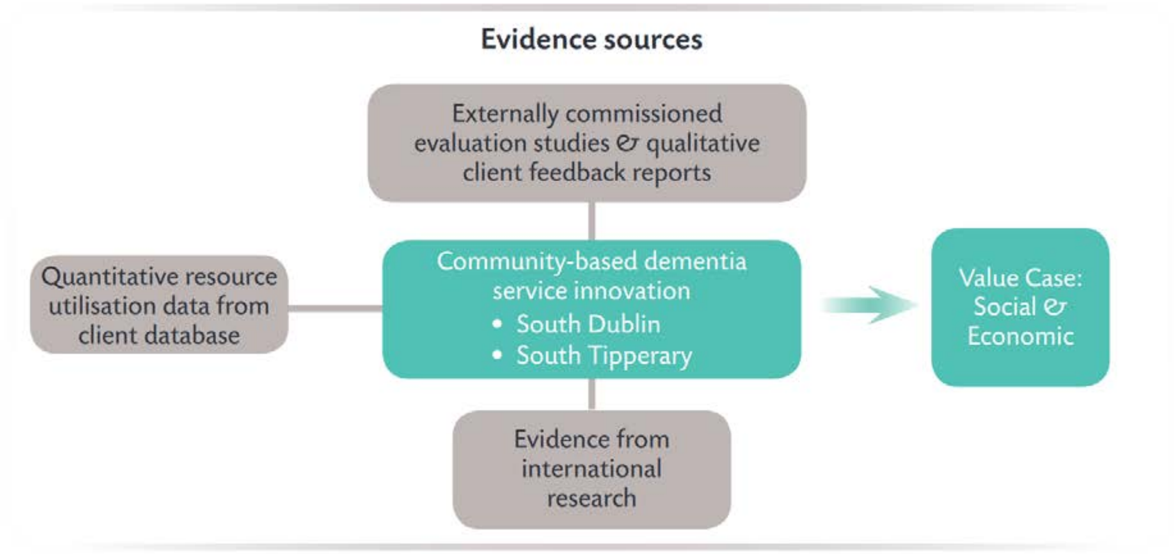


Table 1.1 lists the main project data sources utilised in the report. Chapters 2 and 3 provide further details on these. One core source of data was the overall dementia programme database which logged participants and the details of their service usage over the course of the projects. This database was maintained over the lifetime of each project (approximately three years), with data on service use collected and entered by the project manager in each site. Additional profile and outcome data was collected on a sample of project participants to provide a more in-depth perspective, and this was also included in the database.

Another core element came from the collation, analysis, and synthesis of a broad range of evaluation and feedback data available from the two projects, and from research conducted by external researchers. Separate to the external research, the two projects generated an extensive volume of evaluation data and feedback material from people with dementia and carers. These sources provide both quantitative data and rich qualitative insight into the experience of persons with dementia and their family carers on the projects, and the meaning and value of the services and supports for them.

Table 1.1 Data sources utilised in this study

	Stillorgan/ Blackrock	South Tipperary	Total
	N	N	N
Dementia programme shared database (data collected by projects throughout the lifetime of each project)	110	201	311
Outcome interviews (data collected by the two HSE & Genio Dementia projects on a sample of participants, for inclusion in each project's database)	32	17	49
Feedback surveys conducted by the two HSE & Genio Dementia projects (carried out within each project at different times)	60+	60+	120+
Telecare / Assistive Technology Evaluation (Cullen at al. 2016)	5	25	44*
Initial evaluation of innovative respite care (Cahill et al. 2014, 2014a)	9	8	17
Economic analysis (O'Shea and Monaghan, 2016)	36	59	181*

*Analyses utilised data from all four dementia programme (first phase) projects

For this study, the research team also reviewed the research evidence in the wider literature relating to the types of services and supports offered by the projects. Some additional data gathering and consultation with managers and key workers from the two projects was also carried out.

Collectively, these data sources provide an extensive, multi-perspective view of experiences and impacts for people with dementia and their family carers. They provide a large body of evidence and a unique documentation of the ways that the innovative services and supports facilitated living well with dementia for many, and the value case for dementia care services from provision of these services.

1.3 Structure of the report

The report structures the analysis and results in three main sections. Chapter 2 presents an overview of the programmes of services and supports provided by the two projects. Chapter 3 presents the evidence from the wider research literature and the direct evidence on impacts and outcomes for participants in the projects. Chapter 4 looks at resource allocation and patterns of usage of services and supports by participants in the projects, and examines the social care value and value for money case. The final Chapter provides an overall synthesis and conclusions.

2 Overview of the programmes of dementia services and supports

This Chapter presents an overview of the programmes of innovative dementia care services and supports in the two projects, and profiles the key features of the people using the services and their patterns of service usage. The project portfolios included both 'services' (e.g., home care, therapeutic activity programmes) and broader 'supports' (e.g., befriending, community connecting, choir, and exercise groups). For simplicity, the remainder of this report uses the terms supports and services interchangeably, with the generic term 'support' used to refer to any of the forms of service and support.

2.1 The support programmes in the two projects

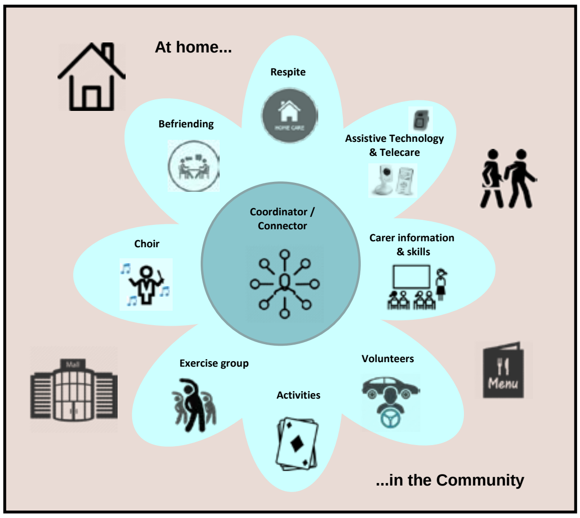
In each project, a consortium comprising staff from HSE services and a range of third sector and community organisations operating within the catchment area oversaw that implementation of the project. Staff from HSE Services for Older People led the *Living Well with Dementia* project in the Stillorgan/Blackrock area of South Dublin. Volunteers were an important element for some of the supports, such as befriending of people with dementia. Staff from HSE Old Age Psychiatry services led the *5 Steps to Living Well with Dementia* project in the South Tipperary area. Trained dementia support workers providing home-based and other supports were a key element.

Overview of supports provided by the projects

- Family carers information and family networking events; family carers training (e.g. 6-week intensive training - Healthy Food Made Easy)
- Volunteer programme (befriending, activity support, drivers)
- Social Supports (exercise group, bridge, Musical Memories choir, creative writing group, art appreciation); Social events (Christmas parties, tea dances, etc.)
- Therapies (cognitive stimulation therapy, art therapy, music therapy)
- Support from health professionals (at Carers events, drop-in clinic, etc.)
- Assistive technology & telecare; Memory Technology Library
- Community connecting supported by Dementia Support Workers
- Home-based supports & Respite (Intensive; Goal focus; Crisis; One off / day off)
- Community awareness

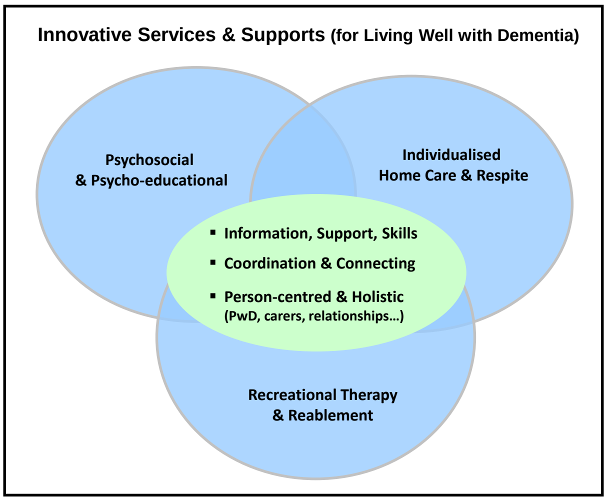
As the titles of the two projects suggest, both had a core focus on supporting people with dementia and their carers/families to 'live well with dementia', with an emphasis on personhood and provision of support in an individualised manner. Figure 2.1 presents a schematic overview of the spectrum of supports they provided. This array of innovative services and supports comprises a broad mix of 'ingredients' or interventions, with a range of potential domains of impact for persons with dementia, carers and families, and for the health and social care system. In the Community Supports Model (Genio, 2016), these supports were collectively described as *personalised supports* under six main headings: timely diagnosis; post-diagnostic support and information; supports to maintain connection; supports to maintain ability; flexible and responsive respite support; and assistive technology.

Figure 2.1 The spectrum of project supports for living well with dementia



Looking at the wider research evidence in this area, these personalised supports in Fig. 2.1 and the coordination function can be mapped onto some of the main categories of interventions in this field, including psychosocial, psycho-educational, recreational therapy and reablement, homecare, and respite (Figure 2.2).

Figure 2.2 Categorising community-based interventions and personalised supports based on research literature



For purposes of this report, the term psychosocial support has been adopted as shorthand, but this encompasses a broad range of supports developed by the projects. It includes a variety of reablement supports on an individual or group basis, with a strong focus on connecting (or re-connecting) persons with dementia with activities in the community. Both projects also allocated substantial resources to personalised home supports, aiming to simultaneously provide respite for carers and positive, person-centred, benefits for persons with dementia.

Both projects provided supports, such as home care and respite, which are already encompassed to some degree in dementia care in Ireland, albeit not generally provided in the personalised manner adopted by the projects. The projects also provided a range of other services and supports less commonly seen within current HSE community dementia care across the country, although many are recognised areas of intervention in dementia care with a growing body of supportive evidence on their contribution and value. Both sites also had a Dementia Coordinator, whose role included providing information and support, connecting the person with services and supports, and embedding personalised supports across a wider area.

Although differing in the mix of supports provided and how they were offered, the two projects shared strong similarities in their focus on living well with dementia. In addition to supports to directly enhance the wellbeing of persons with dementia, this perspective also included home-based, 'respite' type, supports aiming to benefit carers as well. Supports for people with dementia were designed to support the maintenance of ability and connection to life roles and relationships and to provide positive inputs for persons with dementia, at the same time as providing help and a break for carers.

2.2 Usage of supports

The central dementia programme database contains descriptive information and service usage data for the persons with dementia and family carers who used the supports provided by the projects. This is an extensive resource albeit that, due to the broad range of components developed by the projects and the highly tailored nature of some support packages, the full detail of all supports and all contacts may not have been fully recorded.

Stillorgan/Blackrock

The database records 110 people using at least one of a broad range of supports provided by the Stillorgan/Blackrock project. Table 2.1 presents the most frequently used supports. Most participants availed of more than one support, so the percentages add to more than 100 percent.

Table 2.1 Profile of support usage in Stillorgan/Blackrock

	N	%
Information about dementia and services (for main carer)	75	68.2
Core personalised supports		
Exercise	66	60.0
Choir	48	43.6
Befriending	28	25.5
Paid supports (personalised home support and respite)	26	23.6
Total unique persons using any of the supports listed above	95	86.4
Total unique persons (using any of the supports coded in the database)	110	100.0

Source: Dementia programme database

More than two-thirds of participants received information support. Of the other supports, the most frequently used were exercise (for person with dementia and/or for carer), choir, befriending, and paid supports (personalised home support and once-off respite). Overall, 95 people with dementia and carers (86.4%) availed of one or more of these five supports, with various permutations across individuals.

These supports present a spectrum encompassing group activities (choir, exercise), one-to-one social engagement (befriending), and personalised home support / respite. This latter support was of a more intensive nature than the others (described in more detail in section 3.1).

A personalised plan was in place for each person and this personalisation is reflected in the variability in combinations of support used (Figure 2.3). Figure 2.3a shows that while just under one-half (47) of the persons with dementia and carers used only one support, the remainder used more than one support over their time with the project (not necessarily simultaneously). Whether supports were one-to-one or in a group (such as choir), the approach throughout was to tailor supports to the needs of each person at that point in time.

Figure 2.3 Combinations of supports used in Stillorgan/Blackrock

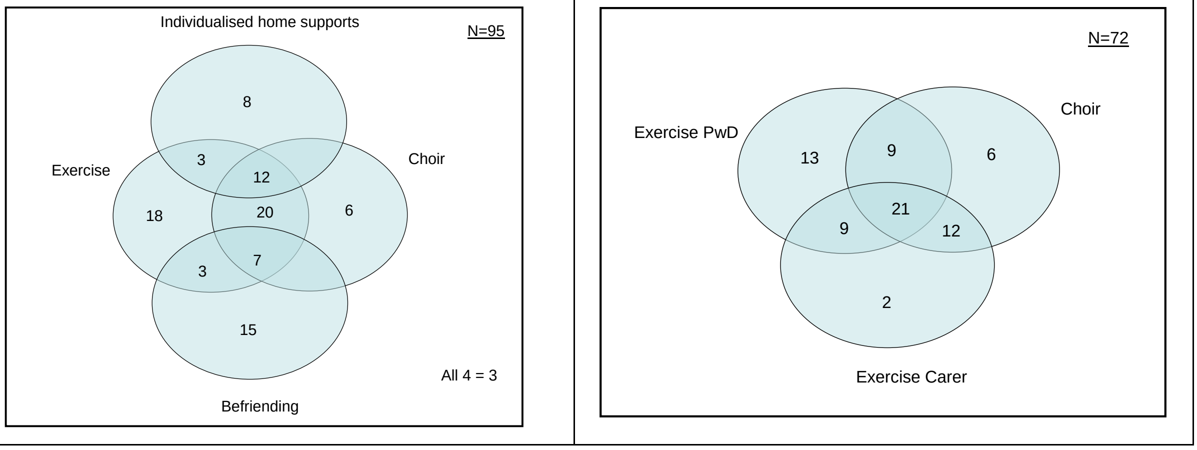


Figure 2.3a
Main combinations of services used

Figure 2.3b
Combined and separate usage (PwD and carer)

The most common support combinations were exercise/choir, exercise only, befriending only, and exercise/choir/home supports. Often, both the person with dementia and the carer participated together in group activities such as exercise; sometimes persons with dementia attended alone, or with a volunteer in some cases; and some carers attended the exercise programme alone, as a support for themselves (Figure 2.3b). A similar situation occurred for choir attendance, but the database does not record how often family carers attended.

South Tipperary

Table 2.2 presents the profile of support usage in South Tipperary over the project period, as mapped in the dementia programme database.

Table 2.2 Profile of support usage in South Tipperary

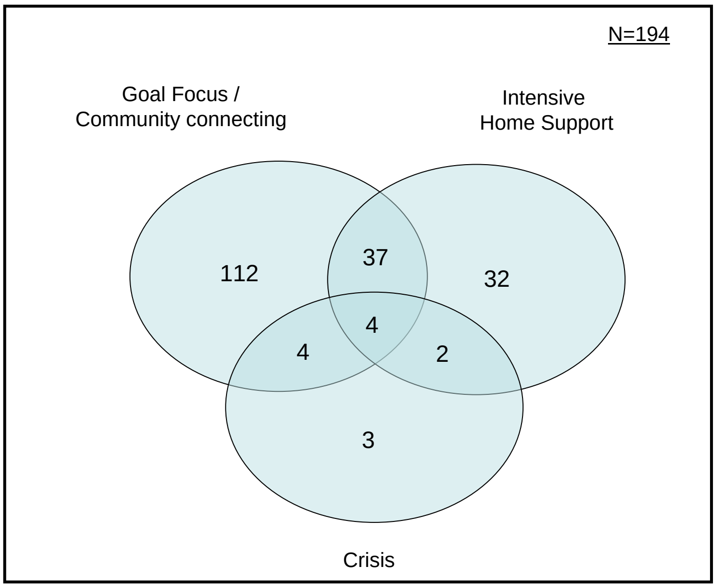
	N	%
Goal focus / Community connecting	157	78.1
Intensive support	75	37.3
Crisis support	13	6.5
Low intensity support	8	4.0
One off / day off support	6	3.0
Total unique persons (using any listed service)	201	100.0
Total unique persons using any of Goal Focus / Connecting, Intensive, or Crisis	194	96.5

Source: Dementia programme database

The database recorded 201 participants in South Tipperary using at least one of the support categories. Some participants availed of more than one support, so the percentages add to more than 100 percent. These supports present a spectrum encompassing socially-oriented activities (community connecting) and individualised, person-centred, one-to-one in-home supports. The types of support are described in more detail in Chapter 3 (section 3.1).

Goal focused programmes, time-limited to 8-12 weeks, were the most frequently used supports (78.1%), often encompassing community connecting as well as home-based support. Next most frequent was more intensive home-based support (37.3%), followed by crisis support (6.5%). Overall, 194 people with dementia and carers (96.5%) availed of one or more of these, with various permutations across these individuals. Smaller numbers used the other types of support – low intensity and one-off day-off. Figure 2.4 presents the profile of participants according to the main combinations of supports availed of.

Figure 2.4 Combinations of supports used – South Tipperary



The largest group were those using only goal focus / community connecting (112), followed by roughly similar numbers using both this type of support and intensive support (37) or intensive support only (32). Small numbers of each combination also used crisis support, and a few used crisis support only.

2.3 Service user characteristics

Table 2.3 presents a profile of the users of supports from the two projects, as recorded in the dementia programme database.

Table 2.3 Service users characteristics

		Stillorgan/Blackrock	South Tipperary
		%	%
Gender	**Male**	49.1	31.7
	Female	50.9	68.3
Age at entry to project	**Mean**	80.9	80.1
	(Range)	(50.2 – 94.6)	(53.3 – 95.3)
Duration in project (weeks)	**Mean**	77.1	94.8
	(Range)	(9.7 – 139.6)	(11.9 – 142.1)
Civil status	**Married / partner**	61.5	44.0
	Widowed	32.1	45.5
	Single	5.5	9.5
	Separated	0.9	1.5
Living situation	**Alone**	28.2	30.2
	With others	71.8	69.8
Main informal carer	**Co-resident**	66.4	68.2
	Lives elsewhere	31.8	26.9
	None	1.8	4.9
Carer gender	**Male**	31.7	35.1
	Female	68.3	64.9
Carer relationship	**Spouse**	55.9	43.5
	Son/daughter	39.2	46.4
	Other	4.9	10.1
Level of need (relative risk of residential LTC)	**Higher**	29.1	27.2
	Lower	70.9	72.8

Source: Dementia programme database

The data in Table 2.3 shows similarities and differences in the user characteristics of the projects. In both projects, the average age was just over 80 years, a little more than one-quarter lived alone, about two-thirds of main carers were women, and in about two-thirds of cases the main carer was co-resident with the person with dementia. In South Tipperary, persons with dementia were more likely widowed; in Stillorgan/Blackrock main carers were somewhat more likely to be spouses. More than two-thirds of persons with dementia in South Tipperary were female, with an even split by gender in Stillorgan/Blackrock.

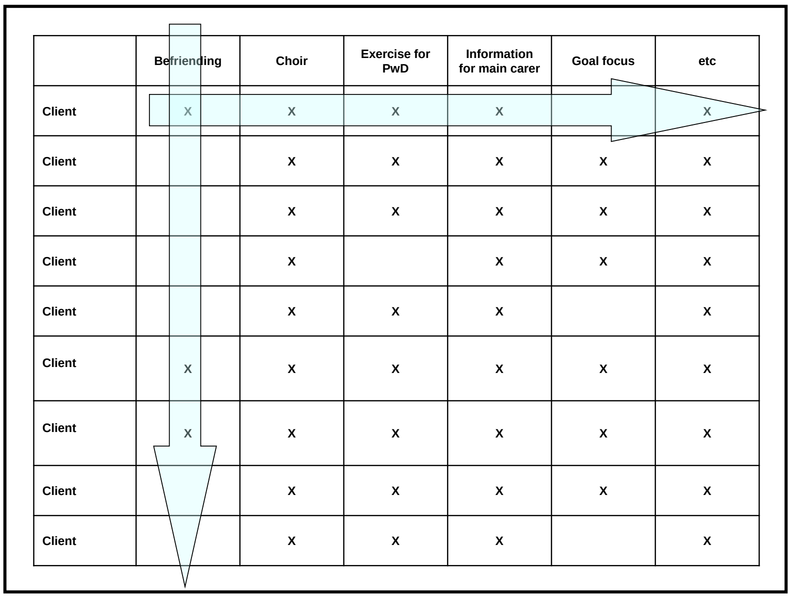
The database also provides some information on aspects of severity/stage of dementia, although the detail and specificity available varies across individuals. The economic analysis study used the available data to estimate risk of entry to long-term residential care, within the next six months, for each person with dementia (O'Shea and Monaghan, 2016). This provides an indicator of level of need, capturing both challenges posed by the person's dementia and capacity of informal carers to maintain the person at home. Based on this, in both sites more than one-quarter of people with dementia were in the higher need category.

3 Outcomes and benefits

The two projects provide a broad canvas of experience of persons with dementia and family carers utilising different mixes of services and supports. This Chapter examines the particular supports in each project, providing greater quantitative and qualitative detail on the outcomes and benefits for users, and considers these supports in light of the available international research evidence.

Each service and support has its own characteristics, and these influence which domains of wellbeing they are likely to impact. Given that many people used more than one support, the analysis in this Chapter applies two perspectives (Figure 3.1).

Figure 3.1 Cross-cutting and service-specific analytic perspectives



	Befriending	Choir	Exercise for PwD	Information for main carer	Goal focus	etc
Client	x	x	x	x		x
Client		x	x	x	x	x
Client		x	x	x	x	x
Client		x		x	x	x
Client		x	x	x		x
Client	x	x	x	x	x	x
Client	x	x	x	x	x	x
Client		x	x	x	x	x
Client		x	x	x		x

The service-specific perspective examines the contribution made by each service in its own right. The cross-cutting perspective examines the collective impact for each person from the combined mix of services they used.

3.1 The contributions of each type of support

The following sections present key results on benefits from each form of support, drawing on evidence from the research literature and from the two projects.

Evidence from the research literature is primarily taken from systematic reviews. These are considered a gold-standard source of evidence, synthesising the results from an entire body of research, and taking into account quality and robustness of the research in reaching conclusions on the evidence and its soundness. Table 3.1 presents an overview of this wider research evidence.

Table 3.1: Overview of evidence from the wider research literature

Type of support	Evidence reviews	Main findings
Personalised home support & respite	*Arksey et al (2004); Knapp et al (2012); Mason et al (2007); Shaw et al (2009); Van't Leven et al (2013)*	• Tailoring / individualising works best • Carers benefit most when care recipient is seen to benefit (dyadic approaches) • Can be cost-effective
Information & skills (psycho-education)	*Pusey and Richards (2001); Selwood et al (2007); Livingston et al (2005); Parker et al (2006)*	• Improved carer psychological wellbeing • Better managing of neuropsychiatric symptoms and challenging behaviours • Focused skills development & psycho-education have best results
Music & singing	*Ueda et al (2013); McDermott et al (2013); Hulme et al (2010); Livingston et al (2014); Victor et al (2016); Vasionytė and Madison (2013)*	• Short-term improvement in mood; cognitive and physiological impacts • Reduction in behavioural disturbance • Evidence of cost-effectiveness, especially music (therapy) to meet needs of person with dementia and carer • Also, broader social / participative value
Befriending	*Windle et al (2011); Lawlor et al (2014)*	• Reductions in loneliness • Positive impacts on mood • Also, broader social / participative value
Exercise classes	*Forbes et al (2013); Farina et al (2013); Heyn et al (2004); Van Uffelen et al (2008); Potter et al (2011); Hulme et al (2010)*	• Improved physical functioning • Possible cognitive improvements • Also, broader social / participative value
Telecare & Assistive Technology	*Davies et al (2013); Poole (2006); Topo (2009); NICE (2015); Cullen et al (2015)*	• Logistical supports for carers (e.g. reassurance; alerting when needed; better sleep; more independence for PwD) • Enabling PwD (e.g. through time orientation)
Arts / creative	*Young et al (2015)*	• Cognitive impacts: attention, memory • Enhanced communication and engagement

The reviews commonly point to important limitations in the available research and evidence-base in this field, including a need for better conceptualisation and measurement of meaningful benefits/outcomes for people with dementia and family carers. The main focus in the wider research literature has been on outcomes for carers, with less attention to quality of life and other areas of potential benefit for people with dementia in their own right. In research on carers, most studies have looked at adverse outcomes; there has been relatively little research on positive (satisfaction) gains for carers, or on relationships between carers and the persons they are caring for. Nevertheless, as indicated in Table 3.1, a growing body of evidence indicates positive impacts for the range of interventions implemented in the dementia programme projects.

The evidence available from the projects is extensive, although generally more of a qualitative nature. It provides essential insight into the ways that the supports have meaningful impacts, and the importance of these for the persons concerned, and in this way usefully complements the literature review findings. There is often strong consistency between the conclusions of the research evidence reviews and the impacts experienced by users of the project supports. Where this occurs, it provides especially convincing evidence of the value of the support in the Irish dementia care context. For example, the research evidence that carers seem to benefit most if respite takes account of both the carer's and care recipient's needs, and where they see the care recipient to be benefiting, is strongly supported by the external evaluation of the respite supports in both sites (Cahill et al, 2014, 2014a) and testimonials from carers (see Box 3.1).

Like many areas of social care, there has been less research on cost-effectiveness and very little in the Irish context. The wider health economics field provides only limited health-related quality of life evidence to guide resource allocation decisions in dementia care (Banergee et al, 2009). This is in part due to a lack of agreed measures for adequately assessing quality of life of persons with dementia (Bowling et al, 2015) and of preference-based metrics for monetising quality of life gains. Recent work has begun to develop such metrics for application in economic assessments in dementia care (Mulhern et al, 2013), but this is still work-in-progress. Nevertheless, there is an emerging body of research evidence pointing to cost-effectiveness of the types of supports offered by the dementia programme projects. Although it is difficult to directly extrapolate findings from one care system to another, the available cost-effectiveness evidence from other jurisdictions may be helpful in guiding resource allocation in this country.

A broad review of cost-effectiveness evidence, covering both pharmacological and non-pharmacological interventions, found varying strength of evidence across a variety of outcome domains (Knapp et al, 2012). Most research was on medication (acetylcholinesterase inhibitors for mild-to-moderate disease, and memantine for moderate-to-severe disease), with evidence of cost-effectiveness through cognitive benefits and associated reduction in dependency and freeing-up of informal carer time. For non-pharmacological interventions, the review found evidence for cost-effectiveness of cognitive stimulation therapy (usually in a social context, and often group-based, with an emphasis on enjoyment of activities), through effects on cognition and quality of life. The review also found evidence for cost-effectiveness of home-based interventions (tailored activity and other occupational therapy programmes to improve functioning of persons with dementia and develop carers skills), through time savings and other benefits for carers. In addition, it found some evidence for cost-effectiveness of respite care in day settings, psychosocial interventions for carers, and coordinated care management.

Other systematic reviews have found evidence of cost-effectiveness for group-based music therapy (Livingston et al, 2014). Value for money analyses also suggest a very positive return on investment from peer support groups for persons with dementia and family carers that involved trained facilitation and activities such as music, games, reminiscence, and exercise (Willis et al, 2016).

3.1.1 Personalised home support & respite

Both projects provided personalised home-based supports as an important component of their programmes. These were additional to, and different from, any standard homecare supports that people with dementia might use. A key difference was the focus on providing direct wellbeing gains for the person with dementia at the same time as providing respite for the family carer.

In Stillorgan/Blackrock, paid care staff, trained in dementia care, provided the personalised home support. The dementia programme database records almost one-quarter of people with dementia (23.6%) receiving this support. This support was needs-led and responsive. As a result, amounts of support utilised by people with dementia varied considerably with a small number receiving a very large number of hours. The average amount of support per person was 440 hours (median = 355 hours), with the support typically provided consistently for an extended block of time. The intensity of usage was an average of about 10.6 hours per week, although with considerable variation across individuals depending on needs.

The South Tipperary project developed a number of forms of personalised home-based supports, and the approach evolved and was refined as the project progressed. To provide the supports, the project used paid 'Dementia Support Workers' from a third sector care organisation who were trained in dementia care.

'Goal focused' support was short-term and structured, designed for people with dementia who could reach a planned goal, sustainable beyond the period of support. Where appropriate, it might include supporting community connection, such as accompanying to activities. The typical programme comprised two hours per week over a 12 week period. The 'intensive' model was a more extensive/extended form of support, targeted towards those with greatest need, and having the potential to delay the need for long-term care. The support was structured according to individual needs; it was in addition to existing supports and did not replace the intended purpose of those supports. Other forms of provision in the project included low level personalised support for people with particular needs which could not be supported in other general dementia services (e.g. more complex dementia with a mental health component), crisis supports, and once-off supports to provide a short break for the family carer.

The majority of people with dementia received either goal focused support (77.1%), which often but not always involved a community connecting component, or intensive home support (37.1%). Average total amount of project support per person in South Tipperary was 55.9 hours. The most common pattern was about two hours per week, with larger inputs for some people receiving intensive or crisis supports.

The research literature provides a range of evidence on the contribution of respite services for carers and care recipients (Arksey et al, 2004; Knapp et al, 2012; Mason et al, 2007; Shaw et al, 2009; Van't Leven et al, 2013). Overall, the evidence indicates that respite care can be cost-effective, but tailoring or individualising of respite is important for optimal benefits. Carers seem to benefit most if the 'respite' takes account of both the carer's and care recipient's needs, and where they see the care recipient to be benefiting. Dyadic approaches focusing on the needs of both parties may be particularly effective.

The evidence from the projects is strongly consistent with that from the wider research literature. External evaluations (Cahill et al, 2014; 2014a), and testimonials from people with dementia and family carers, illustrate how personalised home supports benefited persons with dementia and carers (Box 3.1).

Box 3.1 Testimonials – Dual benefits (for person with dementia and family carers)

"I receive 6 hrs service each week, this gives me time to do my shopping and any other business I have to do. I know I can rely on the girls [Dementia Support Workers] to look after my mother's needs as they always bring a smile to her face. They keep her active by doing activities with her or even taking her for a walk. These things I don't seem to get time to do with my mother." (Family carer)

"*External stimulation and activation with the person outside the family home is very beneficial… By chatting about greyhounds and all topics he would have been interested in. By [dementia support worker] being here she gives me a break as I have to be up several times during the night. Helps us to cope. As for my husband ... the fact of [dementia support worker] helping him reading, etc. has a calming effect for several days."* (Family carer)

"This service is of huge support to us as a family...mam's support worker is so good to my mam and mam is very secure with her. It is fantastic for mam's confidence too and gives us, the family, vital respite if only for a few hours every week, which we really appreciate." (Family carer)

"[Carer] came 3 times a day for 5 days a week, a total of 15 hours. This made a huge difference to both our lives ... My husband enjoyed the visits from the carers. It added variety to his routine and it gave me freedom to do housework, go shopping or meet friends." (Family carer)

"The service is excellent; it works for both the person with dementia and the carer. Having someone to come to your home and give you a break, and know they can care equally as well as you, is great." (Family carer)

The South Tipperary project also conducted its own evaluation on the personalised home-based supports provided by Dementia Support Workers (DSWs), receiving feedback from more than 60 people. For persons with mild and moderate dementia, the research found that value derived especially from having someone else involved other than family. This helped with independence, boosted self-esteem, and enabled connection to the wider community and getting out of the house. Planned support enabled carers to have an organised break, and carers also valued the flexibility and the reassurance they felt when the person with dementia was with the DSW. For persons with severe dementia, a break for the carer was the most frequently cited benefit. Feedback also highlighted the quality of the DSWs and their skills in caring for the person with dementia, especially as respondents felt that it is not easy to get carers who can care for people with dementia.

3.1.2 Information and skills

Both projects included provision of information about dementia, and about available dementia supports, as part of their service. The South Tipperary project did not formally record hours of information support, as such, although staff spent considerable time on this. The Stillorgan/Blackrock project recorded 75 persons availing of information services for the main carer, comprising 68.2% of participants from the project who used any of the supports coded in the database. One component consisted of organised information sessions for family members to meet with care professionals, get information, and build a network of peer support. These carer support groups were usually monthly for the duration of the project and therefore were an ongoing support. The project also provided smaller, self-selected, intensive training programmes on a variety of topics (e.g. nutrition). Some carers attended just one session whereas others attended a number of sessions, including the more intensive skills programmes.

The research literature provides a range of evidence on the contribution of information, skills development and psycho-education programmes for carers of persons with dementia (Pusey and Richards, 2001; Selwood et al, 2007; Livingston et al, 2005; Parker et al, 2006). Positive impacts identified include improved carer psychological wellbeing and better management of neuropsychiatric symptoms and challenging behaviours. Focused skills development and psycho-education appear to have the best results. NICE guidelines in England recommend psycho-education as a support for family carers. Testimonials from family carers from the Stillorgan/Blackrock project show the experienced value of these supports for many carers and persons with dementia (Box 3.2).

Box 3.2 Testimonials - Information and Skills

"I found the talks and discussions at [location] very beneficial in understanding dementia and ways and methods to help in supporting people with dementia stay at home and to be cared for in their own homes, and in particular the services and supports that were available locally in supporting carers and their families ..." (Family carer)

"Learned so much throughout this six week intensive training course. We also shared our own personal experience ... Great support for one another ... It taught my family and myself the right approach, understanding and educated us about the best way to care for and do our best for our family member. It also highlighted what we were doing both right and wrong! By educating us about dementia we became more understanding and better carers so it was a win win situation. We became much happier and more confident carers, which had a knock on effect naturally so our loved one with dementia became happier and more assured that the right care and understanding was at hand! ... A big plus was learning about the advanced stages of dementia so we were well equipped for each stage of dementia as it arrived! (Family carer)

3.1.3 Choir

The Stillorgan/Blackrock project organised the Musical Memories Choir as an initiative to give people with dementia and family carers an opportunity to come together in a relaxed environment and reconnect through music. A Choral Director led the sessions, with support from a team of volunteers. The dementia programme database recorded 48 persons with dementia participating in the choir, usually on a weekly basis; this comprised 43.6% of people with dementia from the project who used any of the supports coded in the database. Choir attendances were recorded in the database as 1.5 hours per person per session. Across users, the average participation timeframe, from first to last session attended, was about 35 weeks. People with dementia varied in attendance patterns, with 'intensity' of usage per person averaging about one hour per week (indicating an attendance rate of about 3 sessions per month) over their period of engagement with the choir.

The research literature provides a range of evidence indicating benefits for people with dementia from music therapy, singing, and participating in a choir. These include short-term improvement in mood, cognitive and physiological impacts, and reduction in behavioural disturbance (Ueda et al, 2013; McDermott et al, 2013; Hulme et al, 2010; Livingston et al, 2014; Victor et al, 2016; Vasionytė and Madison, 2013). Evidence also indicates cost-effectiveness from the social care perspective, and supports the case for delivery of such interventions by health and social care services, particularly the provision of group music therapy that meets the needs of both the person with dementia and their carer. In addition, there are benefits from the more general social and participative nature of choir sessions. Testimonials from people with dementia and family carers from the Stillorgan/Blackrock project show the experienced value of participation in the Musical Memories Choir for many of those who attended, and often for carers and the wider family as well (Box 3.3).

Box 3.3 Testimonials - Musical Memories Choir

*"I enjoy the music and wouldn't miss it for anything. I couldn't go for a while because [carer] was away but looking forward to going back. I like the music and especially the old songs. I used to sing a lot." (*Person with dementia)

"... [husband] just loved the music; he just took off, no inhibitions whatsoever. He was always happy. The support and friendship is marvellous. The staff and volunteers are outstanding". (Family carer)

"Choir is invaluable. Mum has said "I'm really enjoying this". She likes the room, it's so uplifting and she remembers being there week on week. The musicians are marvellous and add extra dimension ... It's important to keep it going. If there's anything I can do to help, I'd be more than happy to help." (Family carer)

"We are delighted with it and [wife] looks forward to going each week. I don't take her; my son does and says she likes it. She comes home in a good mood." (Family carer)

*"Absolutely love it. We haven't missed a Saturday since it started. It's a lovely group of people ... [they] are all great." (*Family carer)

3.1.4 Befriending and Community Connecting

The Stillorgan/Blackrock project provided individual friendship volunteers, carefully selected by a volunteer coordinator, to support people with dementia to pursue their interests and participate in their local community. They either visited the person with dementia each week or accompanied them to an activity based on the likes and interests of the person with dementia. This might involve, for example, going for a walk or playing a round of golf, visiting local attractions, or staying at home and chatting or playing cards. Volunteers received training to ensure they could carry out their volunteering duties effectively. The South Tipperary project provided a 'community connecting' support, delivered by a dedicated community connector function as well as through one-to-one support from Dementia Support Workers for participation in activities.

The database recorded 28 people with dementia from Stillorgan/Blackrock who used the befriending service, constituting just over one-quarter (25.5%) of people with dementia from the project who used any of the supports coded in the database. Data on usage levels indicates an average of 39.2 hours per person using the support, ranging across users from two to 151.5 hours, with an average of about 4.7 hours per month that the service was used. The average participation timeframe, from first to last session utilised, was about 42 weeks.

The research literature does not provide much evidence on one-to-one befriending for persons with dementia, per se. However, a body of evidence is available on the benefits of befriending for older persons more generally. This includes evidence from an Irish randomised controlled trial (RCT) showing a reduction in loneliness (Lawlor et al, 2014), and wider international evidence yielding similar conclusions (Windle et al, 2011). Testimonials from family carers in the projects show how valuable this can be for some persons with dementia (Box 3.4).

Box 3.4 Testimonials - Befriending

"For me the most helpful support has been my two wonderful men, [volunteers] who faithfully come to take [husband] out every week. It is the only male company he has and is very important to us ..." (Family carer)

"... my husband has a befriender who is a gem, one in a million...in the short time [my husband] and I have been involved with the project it has had an enormous impact on our life. [He] now has a focus to his week ... looks forward eagerly to be with his 'friend' on a Wednesday. This is a very special day in the week, he gets up in the morning wondering what they will do and always comes home full of the joys of spring and stimulated - he sits down, writes it up in his journal. It also gives me a break to do some necessary catch up or just meet a friend and have a coffee ..." (Family carer)

"Volunteer programme has been a great benefit to [husband]. He really looks forward to [volunteer's] visit each week. This is something [he] feels he is doing alone ... " (Family carer)

3.1.5 Exercise classes

The Stillorgan/Blackrock project ran a weekly exercise programme that welcomed people with dementia. Carers could also attend, either accompanying the person with dementia or on their own. Participation was on referral by a health care professional in the Stillorgan/ Blackrock area as part of a personalised plan for the person based on their needs and interests. The programme aimed to maintain mobility, dexterity, and the skills needed to carry out activities of daily living such as washing and dressing. The emphasis was on a positive and welcoming atmosphere, with much peer support, cognitive stimulation, and social interaction. Refreshments were also provided and the opportunity for social interaction was an important additional benefit for participants.

The dementia programme database recorded 52 persons with dementia and 44 family carers from Stillorgan/Blackrock availing of the exercise classes, comprising 47.3% of persons with dementia and 40.0% of carers from the project that used any of the supports coded in the database. Exercise attendances were recorded in the database at 1.5 hours per session. The average participation timeframe for persons with dementia, from first to last session attended, was almost 55 weeks (median of just over 42 weeks), with an average 'intensity' of usage of about one hour per week over the period (indicating an attendance rate of about three sessions per month). Carers attended less often than persons with dementia, with the mean number of hours per carer about one-half that of persons with dementia.

The research literature provides a range of evidence indicating potential benefits from exercise programmes for people with dementia (Forbes et al, 2013; Farina et al, 2013; Heyn et al, 2004; Van Uffelen et al, 2008; Potter et al, 2011; Hulme et al, 2010). This includes improved physical functioning and some evidence suggesting possible cognitive improvements. Testimonials from family carers from the project show how valuable this can be for persons with dementia and carers (Box 3.5).

Box 3.5 Testimonials - Exercise classes

"The exercise group is a great way for [him] to be active; to socialise…and provided a structure to his week, that also includes the Musical memories Choir; it gives him a purpose and something to look forward to, it gives him an outing and a way to interact with other people and to feel he belongs to something and to feel valued". (Family carer)

"... my mother looks forward to her weekly visit to bridge and exercise groups. The afternoon suits her body clock, she can genuinely participate in the card games and exercises and the coordinators are so kind to her ..." (Family carer)

"The Tuesday exercise class gave my husband great pleasure and we both enjoyed the friendship and the cup of tea after the class. My husband enjoyed the class and it was lovely to see the smile on his face as he did the exercises. It was great to have something to do, he looked forward to the class and meeting everyone. The project took away the isolation of feeling so alone in dealing with the dementia. My husband died in April and I am so glad we were able to take part and I shall treasure the memories ..." (Family carer)

"... the exercise group is the one we avail of at present; having been involved in sport all his life [husband] enjoys it very much ..." (Family carer)

3.1.6 Telecare and assistive technology

Both projects included telecare and assistive technology within their portfolios of supports. 'Telecare' refers to systems that alert carers when the person with dementia has a need or is at risk; 'assistive technology' refers to stand-alone equipment for use by the person with dementia. The two projects identified people with dementia or carers who might benefit from telecare and provided them with tailored configurations of sensors and other devices. These included bed/chair sensors, property exit sensors, environment sensors (flood, heat, smoke, carbon monoxide), audio-visual monitors, and fall detectors. The South Tipperary project also developed a Memory Technology Library and provided a range of assistive technologies on loan. This included clocks/calendars, one-button radios, medication reminders, and simple-to-use mobile phones.

The research literature provides a range of evidence on the contribution of telecare for carers, including reviews (Davies et al, 2013; Poole, 2006; NICE, 2015; Cullen et al, 2015) and individual evaluation studies (e.g. Woolham, 2005). There have also been a number of Irish studies (Keogh, 2010; Graham et al, 2011). Systematic reviews have found some evidence for impacts on carer stress and strain, and individual evaluation studies have shown the usefulness for carers of the practical and logistical support provided by telecare. The wider research literature also provides some evidence on benefits of assistive technology for persons with dementia, for example, through helping time orientation and prompting or guiding activity and memory, although likelihood of benefit is very individualised (Topo, 2009; Cahill et al, 2007; Carswell et al, 2009).

External researchers evaluated the telecare and assistive technology component of the dementia programme (Cullen et al, 2016). All 24 telecare users in the study reported positive benefits, often major benefits. Most of the 20 users of assistive technology in the study rated it very useful (62.9%) or somewhat useful (20%); one-in-six (17.1%) rated it not useful. Box 3.6 presents some testimonials from users of telecare and assistive technology.

Box 3.6 Testimonials - Benefits from telecare & assistive technology

"This gives her independence. You can monitor but she still feels she is doing her own thing ... I can watch what she's doing and not go near her unless I have to. Otherwise I'd have to be going in and out of the room all the time and that would drive her cuckoo altogether." (Family carer)

"It is peace of mind to know that if she does go wandering ... we will get an alert." (Family carer)

"She'd have a risk of falling ... she can forget to use the frame ... if I'm in the kitchen doing something or in the bedroom or anywhere around the house ... I can go outside to hang up my clothes now, without having the worry of it because I know it's going to beep. I can go out, my garden is out there, my flowers, and I can go out to that, and I can go out with peace."

"I'd be in a bad way without it. I may think it was Monday, instead of Saturday, and that's a regular occurrence. It would be a nuisance if I didn't have the clock. Otherwise I'd turn on the radio - but it might or might not give you the information." (Person with dementia)

"Stopped all the questions - I didn't have to keep saying over and over what day it was. It was nice not to be asked. She used to knock on my bedroom door at night but this stopped once [the] clock was in place." (Family carer)

3.1.7 Arts / creative

A small number of persons with dementia availed of arts-related activities, including creative writing, art appreciation, and art therapy. The evidence from the research literature suggests that arts-based activities can have a positive impact on cognitive processes, in particular on attention and stimulation of memories, as well as enhanced communication and engagement with creative activities (Young et al, 2015). Testimonials from project participants suggest that participants often benefited substantially (Box 3.7).

Box 3.7 Testimonials – Arts/Creative

Creative writing group

"... It helped to re-awaken memories in the group, of people and places forgotten, which was wonderful and very re-assuring, very interesting ..." (Family carer)

"The friendship developed from it and the nice people I met. It stimulated my mind". (Person with dementia)

"It was so good to get [husband] out of the house - he really enjoyed it". (Family carer)

"Enjoyed putting into words my thoughts and happy memories. Putting a story together and reading it back to the group ..." (Person with dementia)

"[He] enjoyed it very much - good for the brain, he has to think". (Family carer)

"[He] does not recall the workshops; however it was definitely stimulating and provided lots of ideas to continue". (Family carer)

"I find it challenging to get him to go to anything with the word 'Dementia' or 'Alzheimer's' in it. But by plodding on and constantly reminding him or bringing him with me to different groups, he enjoys them when he gets there. The difference with this writing group is that he has gone on his own and has no problem doing so, other than being late". (Family carer)

Art appreciation

"... From me and [my husband] - who was totally 'clued in' to the experience. That gave me great pleasure". (Family carer)

"Just hope there will be more events like this; [he] really enjoyed it". (Family carer)

Art therapy

"He does not speak much at home so it's great to see that he did so in this group". (Family carer)

"I enjoyed this group immensely, especially the camaraderie". (Person with dementia)

3.2 Cross-cutting perspective

The evidence presented in section 3.1 demonstrates the strong positive contributions of each of the supports for many people with dementia and carers who used them. It provides useful insight into the multiple dimensions of wellbeing and wellbeing gain in dementia, an area where research and knowledge is still quite limited. It also shows that the experience of living with dementia is likely to have ups and downs, with change and decline over the progressive course of the condition.

The possibility to avail of the most appropriate support, at the right time, was an important feature. This requires the availability of a portfolio of supports to select from, as well as flexibility in their provision to enable an individualised and person-centred approach. The demonstration project funding allowed the HSE services and their partners in the local consortia to do this, without the constraints of the more standardised and less personalised approach that generally characterises usual care in dementia services in Ireland.

Figure 3.2 Mapping of areas of wellbeing gain to types of supports

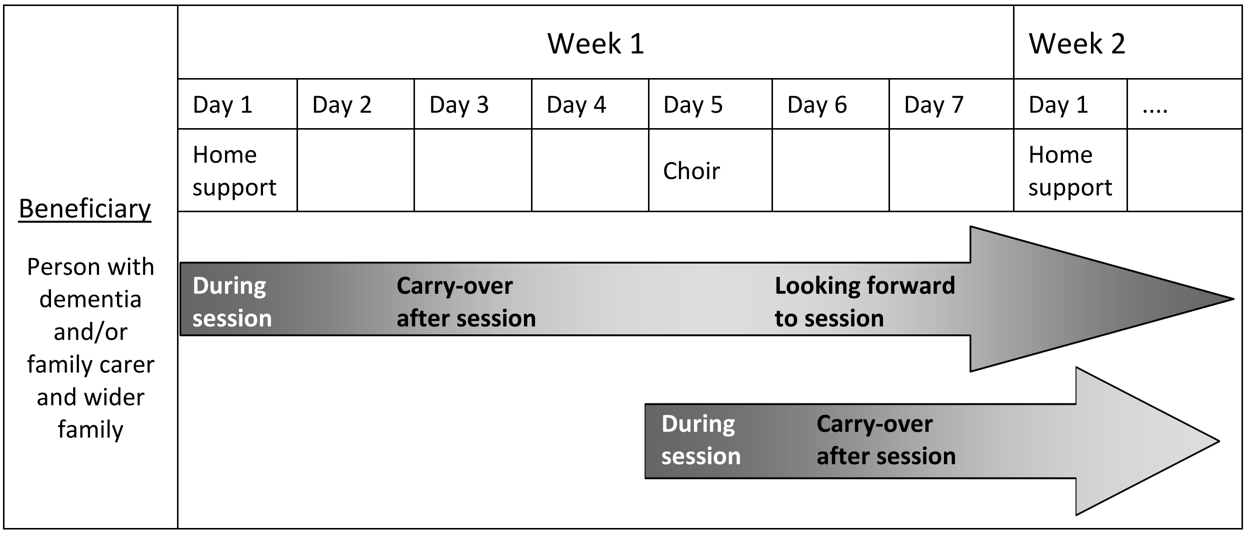
	Home supports			↔			**Social / Community**
	Respite Care	**Respite+, with PwD focus**	**Telecare & AT**	**Info & Care Skills**	**Reable & Recreation**	**Social (PwD only)**	**Social (PwD & Carer)**
PwD Engagement / Reduction in social isolation	?	**XX**	?	?	**XX**	**XX**	**XX**
PwD Mood	?	**X**	**?**	**?**	**XX**	**XX**	**XX**
PwD Everyday functioning / self-management	X	**X**	**X**	?	**X**	?	?
PwD Behavioural / Psychological Issues	?	X	?	**X**	X	?	?
PwD Self-esteem / Confidence (personhood)	?	**X**	X	**?**	**XX**	**XX**	**XX**
PwD General wellbeing / Overall Quality of Life	X	**X**	?	X	X	**X**	X
Carer Strain / Burden	**X**	**XX**	**X**	**X**	X	X	?
Carer opportunity costs	**X**	**X**	**X**	?	X	X	?
Carer General wellbeing / Overall Quality of Life	X	**X**	**X**	X	X	X	?
PwD & Carer Relationships	**?**	**?**	**?**	X	?	?	**XX**

Note: the darker shading, bolding and number of 'X's' indicates a stronger relevance and likely impact of the type of support on the wellbeing domain; a '?' indicates more uncertainty about the relevance/impact.

Figure 3.2 presents a listing of various areas of gain indicated in the family testimonials and the wider research evidence, and provides a loose mapping of these to the different types of support. Participants varied widely in the mix of supports used, as well as in their capacity/ likelihood to benefit from particular types of support. The available data does not allow precise segmentation of individuals (or groupings) according to specific areas of gain for them, or the size of gain achieved, but does indicate that substantial numbers of both persons with dementia and their family carers gained significant benefits in these various aspects of wellbeing.

Figure 3.3 presents a schematic illustration of how benefits may accrue for persons with dementia, and/or family carers and the wider family, from relatively low-level ongoing usage of supports. From this perspective, benefits may accrue in real-time (during a session), for a carry-over period after a session, from anticipation (looking forward to next session), and on a more lasting basis after cessation of usage of the support.

Figure 3.3 Episodic accrual of benefits



The characteristics of the person with dementia will influence whether these benefits accrue, for example, whether they have a memory of participation after a session and/or capacity to anticipate the next session. Even if these cognitive capacities are absent, there may nevertheless be carry-over of mood-related benefits after sessions. The testimonials from persons with dementia and family carers provide many examples of how these forms of benefit accrued, and the variation across persons with dementia in this regard. The wider research literature also provides evidence of mood-related impacts and underlying physiological changes from some supports, such as music and singing (Vasionytė and Madison, 2013).

3.2.1 Some key areas of benefit

Table 3.2 presents a framework identifying some key areas of benefit for persons with dementia and family carers, as well as the combined benefits for both parties through gains linked to familial relationships. This provides an organising framework for extracting and presenting a more global and cross-cutting perspective on benefits achieved, to complement the more differentiated analysis by specific support type presented earlier.

Table 3.2 Some key areas of benefit for persons with dementia and their carers

Person with Dementia	▪ enhanced personhood ▪ gains in subjective wellbeing ▪ enabled to live longer at home
Family Carers	▪ reduced burden and negative impacts on wellbeing ▪ enhancement of more rewarding aspects of caring ▪ reduction in opportunity costs of caring
Couples/Families	▪ relationship-related gains ▪ satisfaction from sustaining living at home

Benefits for Persons with Dementia

Various characteristics of dementia make it challenging to assess the impacts of interventions for persons with dementia. Cognitive changes often limit the extent to which persons with dementia can provide direct appraisals, so evidence is often based on observation or proxy reports by family carers or others. Development of measures that better capture quality of life has been an area of focus; the DEMQOL instrument, for example, captures feelings, memory, and everyday activity and experiences (Smith et al, 2007).

From the perspective of living well with dementia, research and service developments have focused on enhancement of personhood and subjective wellbeing (happiness/pleasure or so-called 'hedonic' benefit) as two important outcome domains for persons with dementia. Many of the testimonials from persons with dementia and carers in Section 3.1 indicate these types of gains for persons with dementia using particular supports. This section collates some of these, as well as some additional testimonials, to illustrate personhood and subjective wellbeing gains provided by the project supports.

Personhood

The work of Kitwood is especially associated with the view that dementia care, and social perspectives on dementia more generally, should focus on enhancing the personhood of people with dementia (Kitwood, 1997). Promoting personhood and provision of person-centred care are given a central place in the Irish National Dementia Strategy (Department of Health, 2014). Types of support that may particularly contribute to personhod include care that combines personalised supports, provision of reablement and recreational inputs, and various social activities. These include one-on-one and group activities, and may be for the person with dementia only, or for both person with dementia and family carer. A number of testimonials from persons with dementia and family carers provide vivid illustratration of personhood gain through the projects' supports (Box 3.8).

Box 3.8 Testimonials - Personhood gain

"You open a box that has been closed for 50 years and all the memories come out ..." (Person with dementia - engaging in creative arts)

"Mum was stimulated in a way different to home/family stimulation. That made her come alive again as she used to be. For all the time that Mum has lost to us, these occasions gave us precious moments when we got her back and she found herself again ..." (Family carer)

"Without the project, [brother] would definitely have been in a nursing home by now, or even died. Instead, he's living a supported, independent life that's full of meaning. We can support him too because we're not alone ... [brother] "a different person" ... You almost wouldn't recognise him. At the Christmas party, he was up singing and dancing. I couldn't believe it." (Family carer)

"Volunteer programme has been a great benefit to [husband]. He really looks forward to [volunteer's] visit each week. This is something [husband] feels he is doing alone. The exercise class again [husband] enjoys as it is something he attends alone ..." (Family carer)

"The project has vastly improved [husband's] quality of life; it has helped restore his confidence within himself and given him a feeling of self-worth". (Family carer)

"Enjoyed putting into words my thoughts and happy memories. Putting a story together and reading it back to the group ..." (Person with dementia)

Subjective wellbeing

Subjective wellbeing perspectives focus on positive wellbeing of persons, as measured by life satisfaction, happiness, and other such indicators. The testimonials show the happiness and pleasure provided to many persons with dementia from the project supports and participation in activities (Box 3.9).

Box 3.9 Testimonials - Subjective wellbeing (happiness and pleasure)

"I know I can rely on the girls to look after my mother's needs as they always bring a smile to her face. They keep her active by doing activities with her or even taking her for a walk. These things I don't seem to get time to do with my mother." (Family carer)

"He looks forward eagerly with his 'friend' on a Wednesday. This is a very special day in the week; he gets up in the morning wondering what they will do and always comes home full of the joys of spring and stimulated". (Family carer)

"We enjoyed the social events so much, Tea dances, parties etc. Also, support on hand for carers at the exercises ... [Husband] just loved the music; he just took off, no inhibitions whatsoever. He was always happy. The support and friendship is marvellous". (Family carer)

"I don't always go with her as you know – the rest of the family take her sometimes but we all agree that she (mother) loves it. She is comfortable and feels great ownership of the choir. She comes out feeling great ..." (Family carer)

Aspects of this may include enjoyment in the moment, general and sustained mood uplift, and having something to look forward to. Frequency and continuity of access to the support or activity will influence this. Cognitive capacity and memory will also affect the potential for these types of gain. For example, some people may have no memory of an activity even if they got great pleasure in the moment. In such cases, they are unlikely to derive benefits from looking forward to the next session, although they may maintain more generalised mood benefits in the period between sessions. All forms of benefit are of value, even when fleeting and in-the-moment.

Benefits for Family Carers

Family carers of persons with dementia may benefit in a variety of ways from supports provided by dementia care services. The wider research literature suggests that reduced burden and mitigation of negative wellbeing impacts, and reduction in opportunity costs of caring, can especially contribute to better quality of life for carers (Farina et al, 2017). Family carer testimonials show how the project supports provided substantial benefits in these areas for many family carers (Box 3.10). The supports could help them to better manage the care process, reduce some of the burden and strain, enable them to have some life of their own, and provide opportunities for enjoyment and pleasure. Carers also reported benefits from not feeling alone and from having some sense of hope and reassurance.

Box 3.10 Testimonials - Reduction of burden & opportunity costs

“It takes a lot of pressure off. Being able to leave the house.” (Family carer)

“Took off some pressure - got out extra day per week - felt happier - a sense of good wellbeing for the person.” (Family carer)

“I get to visit my friends and family on Monday...a great help to me and my sanity” (Family carer)

“Peace of mind regarding school run in the evening.” (Family carer)

"*It has given me time for myself to be able to go out for the time that the person is there, knowing my Mum is safe.”* (Family carer)

“The service is excellent, it works for both the person with dementia and the carer. Having someone to come to your home and give you a break and know they can care equally as well as you is great." (Family carer)

"Because really, before this, the way I was feeling was “I can’t do this”. So this (monitor) has helped the whole situation, you know. It works both ways. If I hadn’t been able to look after him he wouldn’t be able to be there you know ... I was stressed out at night running up and down...this has been my saviour you know. It’s very good." (Family carer)

"[Made] a big difference. We no longer felt we were alone and the source of information was very reassuring ..." (Family carer)

"... Hope for the future and reassurance that you are not alone". (Family Carer)

Relationship and wider family benefits

The testimonials show that the project supports often provided benefits for both the person with dementia and family carer, as a couple, and sometimes for the wider family as well. These relationship gains may often be as important and valued as individual benefits for any one of the parties (Box 3.11).

Box 3.11 Testimonials - Relationships / benefits for all parties

"Joining the musical memories choir has brought us both joy and the social aspect is very important and of course the tea dance, lovely and still able to tread a measure especially the Waltz ... It has broadened our horizons ..." (Family carer)

"We both went to some of the social events and really enjoyed the interaction and the dancing ..." (Family carer)

"The project managers helped us to get things in perspective and consequently my relationship with [wife] has improved and there is a lot less conflict now and I've learned to steer clear of trigger points for conflict ... (Family carer)

"We love the art appreciation ... attended every session and look forward to many more. It really brings out a spark in [husband]. We also love the tea dances ..." (Family carer)

In addition to the direct forms of wellbeing gain described above, the evidence also shows the more global benefits for families deriving from the person with dementia remaining living at home, and from the family carers' ability to maintain this. A number of the family testimonials underlined this aspect (Box 3.12).

Box 3.12 Testimonials - Satisfaction from person with dementia living at home

“It has helped to keep Dad at home as we do not wish to put him into care. It has also taken pressure off the family as we all get a night off each week.” (Family carer)

“It has been essential to my being able to keep [husband] at home, was considering a Nursing home before this began. Keeping [him] at home has been so important for both him and me.” (Family carer)

"... [husband] has Alzheimer's for about seven years and for the past two years I could not have coped without the Musical Memories Choir, the social events - Christmas parties, Tea Dances and various other activities ..." (Family carer)

"Information and support ... ; exercise class and choir were also invaluable both for [husband] and me ... Looking after someone at home without all of the above supports would, in my view, be impossible ... Keeping patients out of nursing homes and hospital must save money and provide appropriate care". (Family Carer)

"... if she had not had the happy experience of linking up with the LWwD groups it is hard to see if she could have continued living independently ... I received a lot of support because at times I felt overwhelmed by the responsibility and stress ... I have no doubt [wife] would be in a home now without their support ..." (Family Carer)

Notwithstanding the positive results, it must be acknowledged that dementia is a degenerative disease with increasing care and support needs as the condition progresses. The supports provided by the projects could not, and were not designed to, solve all the problems and challenges of caring for persons with dementia. Despite the enormous value and benefit reported by family carers, families still provided a huge number of caring hours (O'Shea and Monaghan, 2016). Interviews with a sample of people using the supports in each project - mainly the group at high risk of moving to long-stay residential care - found that many carers experienced a substantial ongoing burden from caring. This was particularly where there were other demands on carers (such as work, family commitments, their own ill-health or where the person with dementia exhibited responsive behaviours that were challenging for carers) (Box 3.13).

Box 3.13 Outcome interviews: caring can be difficult, even with the project supports

Earlier interview	Later interview
Very difficult, person is frustrated and discontent, constantly agitated. Very hard to manage him.	He is very difficult to manage.
Very tiring as she is very busy with her job and she has a child who has a chronic illness.	Time consuming. Good family support. They have a formal care system in place, which makes the caring much easier.
Very tiring. Three family members maintain a rota at night. Always someone in the house overnight.	Can be tiring. Daughter is the key person in mum's care. Rota system continues for overnight care.
Very busy lives with jobs and young families, but it’s a pleasure.	Involves a lot of co-ordination. Can be very tiring with a young family and a full time demanding job.

Despite these challenges in caring, other data from the survey suggests that carers' health and wellbeing generally remained fairly constant over the time period between interviews. The project supports may have helped many family carers to continue caring for longer without major negative consequences for their health and wellbeing. If not overburdened and overwhelmed by the challenges, family carers can gain many positives from supporting the person with dementia to live as well as possible.

3.2.2 Benefits from a combination of supports

The direct feedback from project participants shows how a combination of supports was beneficial for many (Box 3.14). The wider research literature also provides evidence of the value of multi-component approaches (e.g. Cooke et al, 2001; Smits et al, 2017). A broad systematic review of interventions for carers of persons with dementia used meta-analysis to integrate the results of 127 studies (Pinquart and Sörensen, 2006). It found that a range of interventions tended to have significant but small effects on burden, depression, subjective well-being, carer ability/knowledge, and symptoms of care recipients. Only multi-component interventions reduced the risk for institutionalization. Another extensive review covered a range of interventions to assist caregivers to support people with dementia living in the community (Parker et al, 2006). They found evidence to support the use of well-designed psycho-educational or multi-component interventions.

Box 3.14 Testimonials – Benefits of using a variety of services and supports

"Volunteer programme has been a great benefit to [husband]. He really looks forward to [volunteer's] visit each week. This is something [husband] feels he is doing alone. The exercise class again [name] enjoys as it is something he attends alone ... Community awareness in Stillorgan shopping centre is excellent. When I booked an eye test I was given extra time and the staff were very understanding ... Living Well have supplied a tracker for [husband] which has given all the family great comfort knowing that if he did get lost we would be able to find him as soon as he was missed ... Living Well have provided me with two mornings per week for [husband] which has allowed me to continue working outside the home. This has helped in making life as normal for all the family as possible. Social events allow both carer and client to meet people in a similar situation and be relaxed". (Family Carer)

"I found the family carers' information nights very helpful ... It has made a big difference in that one doesn't feel one is battling this awful disease alone. There is always help and support from 'Living Well with Dementia' at the end of the phone, and people will listen to you and it's very obvious that everybody involved really cares about the dementia patient ... My husband and myself have been attending the Musical Memories Choir since it started two years ago and it is so much part of our Saturday now and we really look forward to it, as the weekend can be difficult enough ..." (Family Carer)

"[Family Carers Information and family networking events]: The information was very relevant ... At the time I was finding various aspects of my wife's illness very challenging, e.g. trying to encourage her to eat, and I found the presentation very timely and very relevant. The project team members were genuinely interested in helping me and I sensed their caring and compassionate qualities. It was a relief to meet people who were experiencing the same challenges as a carer. Social events, simply to relax with the project team and other carers ... Respite, once off, great help ... help to deal with pressures that otherwise I would not have been able to cope with ... As a result of the education I received, I was better prepared for the day to day challenges of my life as a carer, and therefore my wife received more consistent care. The carers gave me valuable support and breathing space. The respite reduced the pressure I was living with". (Family Carer)

4 Resource allocation and value case

The evidence presented in Chapter 3, both from the projects and from the wider research literature, shows the benefits and positive outcomes that individualised and person-centred supports can provide for persons with dementia and family carers. This Chapter looks at the supports provided by the projects from a resource allocation and value for money perspective. It presents an analysis of the quantities (hours) of support used by participants and the patterning of this over time, and looks at the economics and value case for these types of supports.

4.1 Amount and type of support usage

Reflecting the individual tailoring of support, both projects showed a very broad distribution across participants in total hours and composition of support utilised (Figures 4.1 and 4.2). Tables 4.1 and 4.2 present the data on hours of support for different types of support.

Table 4.1 Hours of support for each type of support: Stillorgan / Blackrock

	Paid	Befriending	Exercise (PwD)	Exercise (carer)	Choir	Total
Mean (median)	439.9 (354.75)	39.2 (36.5)	54.6 (39)	26.8 (11.25)	36.7 (17.25)	192.8 (73)
Range	12 - 2108.25	2 – 151.5	1.5 - 171	1.5 - 129.5	1.5 – 120	1.5 - 2117
Total (%)	11,436.9 (62.4%)	1,098.5* (6.0%)	2,839.5 (15.5%)	1,179 (6.4%)	1,760 (9.6%)	18,314 (100.0%)
# of persons	26	28	52	44	48	95

* volunteers also contributed an even larger number of hours driving and accompanying to activities

Table 4.2 Hours of support for each type of support: South Tipperary

	Goal focus / Connecting	Intensive	Other	Total
Mean (median)	34.7 (24)	60.8 (50)	49.1 (24)	55.9 (29)
Range	2 - 216	4 - 231	2 - 480	2 - 488
Total (%)	5,451 (48.5%)	4,557 (40.6%)	1,227 (10.9%)	11,235 (100.0%)
# of persons	157	75	25	201

Overall, people with dementia and carers in Stillorgan/Blackrock tended to utilise a greater number of hours of personalised support over the project period (mean = 192.8; median = 73) compared with those in South Tipperary (mean = 55.9; median = 29), but the latter project was supporting a larger number of clients. In both projects, the personalised support packages provided were additional to any ongoing formal supports people with dementia may have been receiving through 'care as usual'.

Figure 4.1 Total hours and composition of supports used: Stillorgan / Blackrock

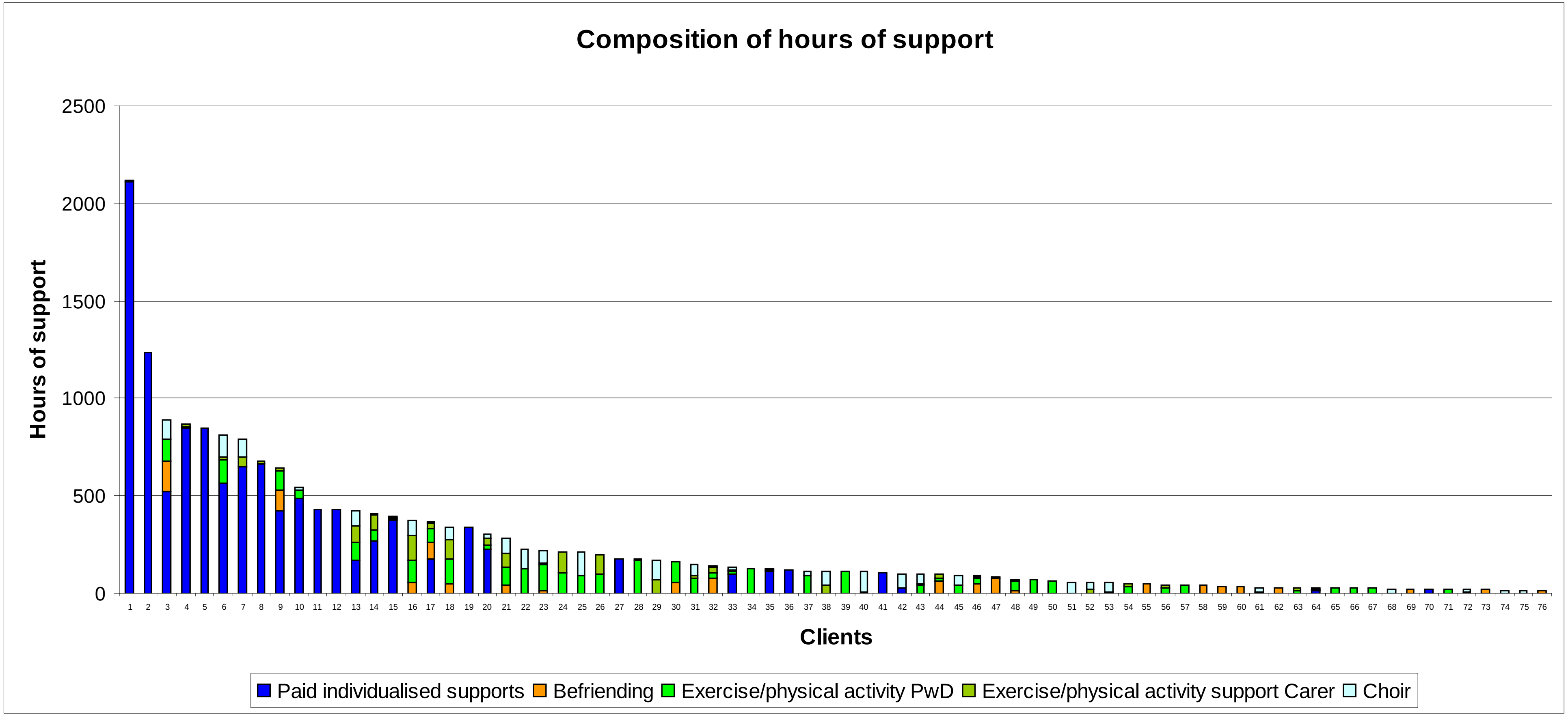
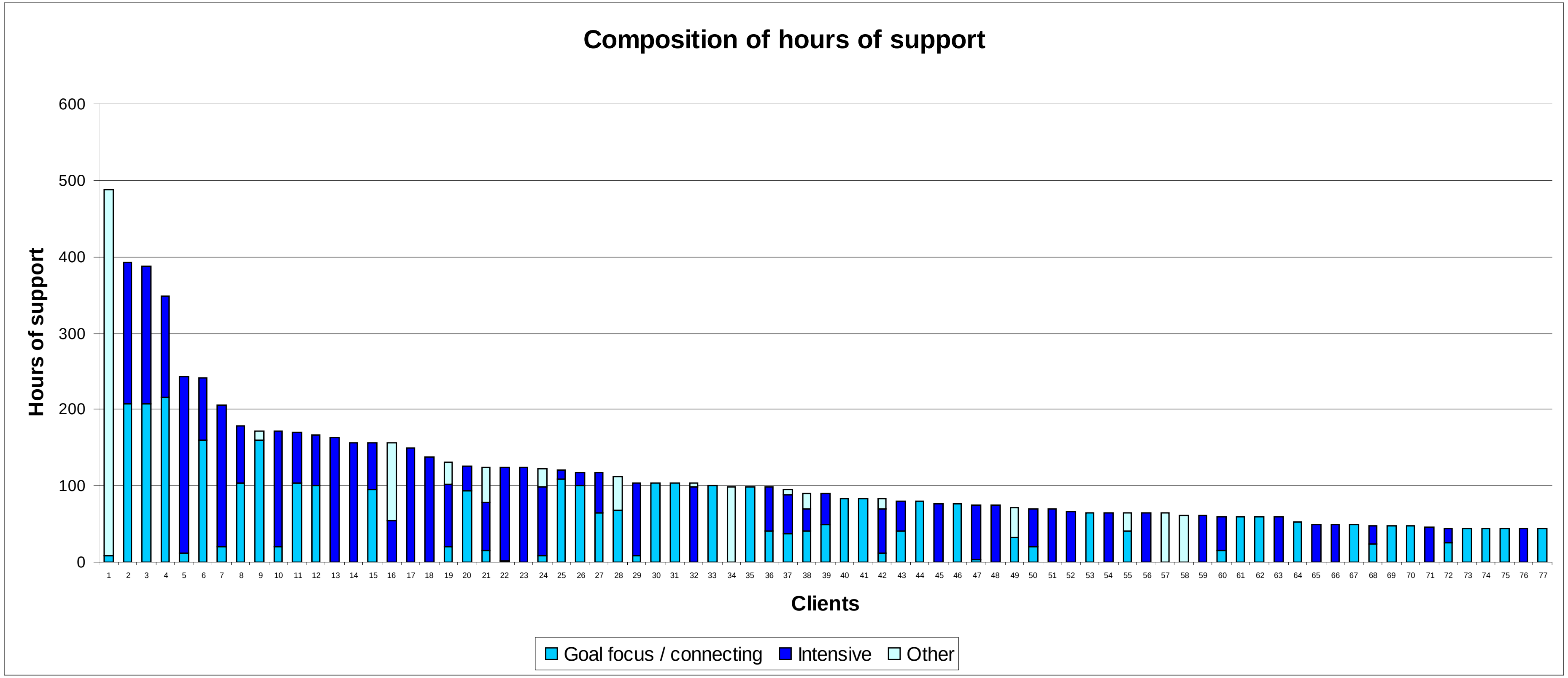


Figure 4.2 Total hours and composition of supports used: South Tipperary



Some supports were in a group setting as part of a personalised plan (e.g. exercise, choir), but the largest share was in the form of one-to-one supports (personalised home supports, befriending/connecting). In Stillorgan/Blackrock, for the five core supports provided, paid personalised home support hours comprised more than 60 percent of the total hours, with a small number of people with dementia receiving a very large number of hours of paid homecare. In South Tipperary, the two main forms of personalised home support (goal focus/connecting and intensive) comprised almost 90 percent of the total hours provided.

Persons with dementia became participants in the projects on a rolling basis over the course of the programmes. They varied in the duration of their involvement and in the intensity of their support over the period they were with the project (Table 4.3).

Table 4.3: Time on project and personalised support usage

	Stillorgan/ Blackrock	South Tipperary
Weeks on project - mean (median)	76.5 (81.9)	94.8 (101)
Total hours used	18,314	11,235
Number of persons	95	201
Intensity of support usage in hours per person/week - mean (median)	2.6 (1.0)	0.6 (0.5)

Participants in South Tipperary tended to have longer registration with the project than participants in Stillorgan/Blackrock, as measured in weeks from first registration with the project until they left, or until the end of the project for those who were still registered at the time the project ended. The average registration duration was 94.8 weeks in South Tipperary and 76.5 weeks in Stillorgan/Blackrock. Intensity of support usage, measured in hours per week per person over the entire duration they were with the project, tended to be considerably higher in Stillorgan/Blackrock (mean = 2.6, median = 1.0) than in South Tipperary (mean = 0.6, median = 0.5). For Stillorgan/Blackrock, in particular, the median is probably a better measure of central tendency than the mean because a small number of persons received a very large amount of paid homecare hours.

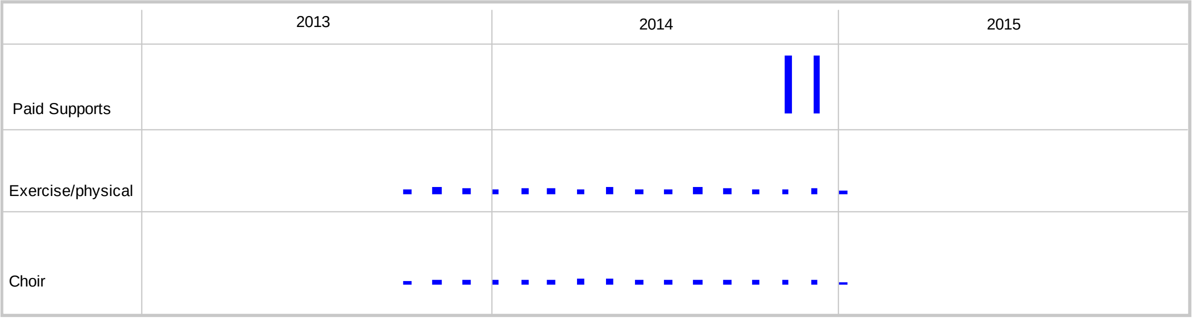
There was a similar pattern when intensity was measured for the period covering from when a person with dementia first received any support hours until they ceased receiving supports. This 'active' duration is an approximate calculation based on the dates indicated in the database, which do not always allow precise calculation of the duration over which the supports in question were utilised. The approximate 'active' duration extended over more weeks in Stillorgan/Blackrock (mean = 56.0; median = 53) than in South Tipperary (mean = 33.7, median = 18). The mean intensity of support usage, in hours per week per person over their 'active' period, was considerably higher in Stillorgan/Blackrock (3.9) than in South Tipperary (1.9). However, the pattern reverses when the medians are compared, with a median of two hours per ‘active’ week in South Tipperary and 1.7 hours per ‘active’ week in Stillorgan/Blackrock.

Patterns of support usage over time

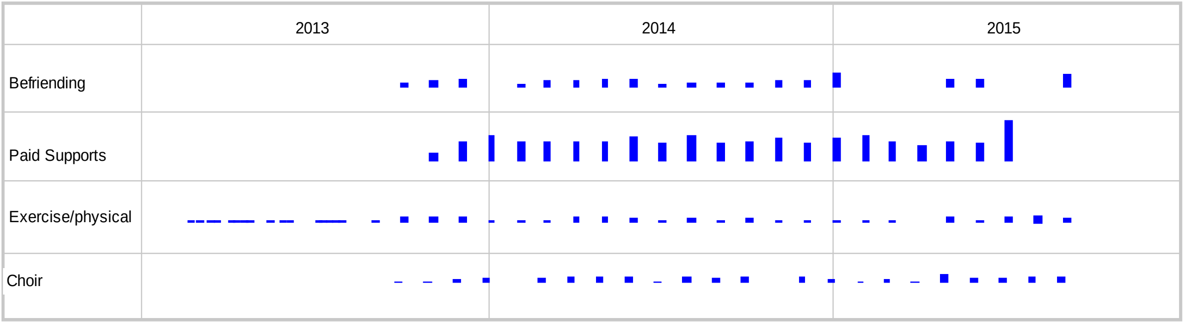
Figure 4.3 presents a dynamic view of the patterns of support provided over time to people with dementia and carers in the two sites, derived from the data recorded in the database. It shows the approximate usage periods for each support, with height providing an indication of the number of hours of support provided. The selection of participants illustrated show some of the variation in allocation and usage of supports, both within and between the two projects.

Figure 4.3 Illustrative participant profiles - patterns of support usage over time

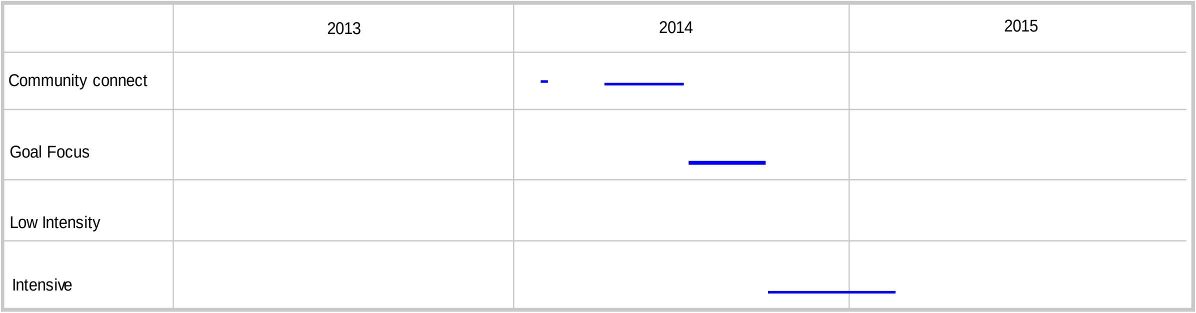
Choir and exercise usage for more than a year, large intensive input of home care towards the end



Multiple support usage over 2 to 3 years, including exercise, befriending, choir and home care



Community connecting, then goal focus home support, then intensive home support



4.2 Economic analysis

Living well with dementia is generally associated with living at home in the community rather than in long-term residential care. For most people with dementia and their carers/families, this is the preferred situation for as long as possible. Nevertheless, many people with dementia eventually move to residential care and this is evident in the proportion of older persons in long-term residential care who have dementia.

A separately conducted economic analysis of project costs focused on people with dementia identified as having high risk of admission to residential care in the near-term (O'Shea and Monaghan, 2016). It concluded that the projects potentially helped avoid/delay entry to long-stay residential care for many of these individuals. The feedback from family carers presented in Chapter 3 provides corroboration for this.

As residential care represents an expensive form of care provision, delaying its use can result in substantial cost savings. For the four dementia programme projects combined, the economic analysis estimated potential cost savings of more than €3 million, for 181 people for an estimated period of approximately 15 months, from avoidance/delay of move to long-stay residential care in comparison with HSE and project support services. About one-half of this potential saving accrued from the Stillorgan/Blackrock and South Tipperary projects. These figures point to the potential for significant cost savings across larger numbers of people and/or for longer periods of time.

Whilst these potential savings are substantial, it would be inappropriate to blindly aim to keep persons with dementia at home without considering the best interests of all concerned, both the person with dementia and family carers. For most people with dementia and their families, remaining living at home for as long as possible is a valued outcome in its own right, although the value of this is strongly influenced by supports to live well in everyday life with dementia. Maintaining persons with dementia at home for longer also has a cost, particularly for family carers who still provide the bulk of care to people with dementia in Ireland (Connolly et al, 2014). The economic analysis showed the substantial contribution made by family carers that facilitate these care system savings, and the importance of supporting family carers through both standard home care and the types of personalised supports provided by the projects.

4.3 Wellbeing gain

The economic analysis suggests that programmes of personalised supports are likely to yield a strong return on investment through cost savings from delay or avoidance of a move to residential care. However, cost considerations are only one element of what needs to be taken into account when making decisions about what type of care should be available and in what setting. The wellbeing gains for persons with dementia and family carers are a core part of the value case for the provision of individualised and person-centred supports in addition to standard care.

At an average of between one to two hours per week per person, the overall levels of additional personalised support provided in these projects were not very large. Nationally, the required resources to mainstream the provision of this form of support, in addition to the ‘usual’ social care allocation for older persons, would appear to be quite modest.

Overall, given the substantial wellbeing gains reported by many people with dementia and carers, it seems that relatively marginal additions of personalised supports may generate very high yield. There is a strong case for considering resourcing the provision of low intensity supports that can reach large numbers of people with dementia and their carers, particularly at earlier stages.

4.4 Value for dementia care system and supporting dementia policy

Given the economic case and wellbeing gains, the innovative programmes provide substantial value, not only for the person with dementia and family carer, but also for the wider dementia care system and in supporting achievement of dementia policy objectives. For the care services, there is considerable value from having something positive to offer people with dementia. For the wider care system, these approaches facilitate fairer sharing of caring between the care system, family carers, and communities more generally. Separately and in combination, the demonstrated impacts and outcomes strongly support the case for mainstreaming these approaches in order to deliver on the objectives of the National Dementia Strategy.

4.5 Implementation

In the two projects, the implementation framework included a coordination function (such as a dementia care coordinator) and provision of a large number of hours of support through a variety of individual-based and group-based interventions. HSE professionals led the programmes and were extensively involved in the various elements. Home-based supports were delivered in a variety of ways, including paid Dementia Support Workers and a managed pool of trained volunteers. Outsourcing arrangements were a central feature, with HSE funding and quality assuring support services delivered by third parties. Contributions from the community sector and other stakeholders leveraged a significant contribution of in-kind resources and voluntary inputs which did not come from ‘health funding’, but a central organising and funding role by the HSE care services was essential. The wider system within which the individualised and person centred supports were provided is described as a Community Supports Model (Genio, 2016). These approaches proved feasible and effective, and could operate in HSE local areas across the country.

5 Summary and conclusions

The dementia programme projects had a core focus on supporting people with dementia and their carers/families to 'live well with dementia', with an emphasis on personhood and provision of support in a personalised manner. Although innovative in the Irish context, the broad mix of supports provided by the projects encompassed recognised areas of intervention in dementia practice and research. These include psychosocial and psycho-educational interventions, personalised homecare and respite, and recreational therapy and reablement approaches.

Both projects allocated substantial resources to personalised home supports, aiming to simultaneously provide respite for carers and positive, person-centred benefits for persons with dementia. They also provided supports to connect (or re-connect) persons with dementia with activities in the community, and a range of other social and therapeutic supports. Participants included a broad range in their severity of dementia and associated capacities, interests, and needs, including a substantial number with a high risk of entry to long-stay residential care in the near-term. Depending on circumstances and needs, people with dementia varied widely in combinations of supports used, and in levels and patterns of usage.

The research on the projects conducted in this study, together with the results from the wider literature review, provides new knowledge and evidence on the impacts and value for money of personalised supports in dementia care in Ireland.

Impacts for persons with dementia and family carers

Analysis of an extensive body of direct evaluation evidence from the projects found that the programmes of personalised supports helped many persons with dementia and their family carers to live well, or at least a lot better, with dementia. This included benefits for the person with dementia, for family carers, and at the family level. Each form of support proved useful for many people who used it. In addition, many people used a number of the supports on offer and gained substantial value from the possibility to select and tailor support packages that met their preferences, circumstances, and needs.

The results are congruent with the evidence from the wider research literature indicating the value of multi-component programmes, the importance of tailoring interventions to relevant and achievable domains of gain, and the particular value from interventions that target gain for both the person with dementia and family carer.

Resource allocation and value for money

Detailed data on support hours provided to each person enabled analysis of the economics and value for money of the programmes of personalised supports. Overall, the levels of support utilised by participants in the projects averaged between one to two hours per week, but with flexible access and wide variation across individuals in the mix of supports and total number of hours of support used. Nationally, the required resources to mainstream the provision of this form of support, in addition to the ‘usual’ social care allocation for older persons, would appear to be quite modest.

A separately conducted economic analysis of project costs focused on people with dementia identified as having high risk of admission to residential care in the near-term (O'Shea and Monaghan, 2016). It concluded that the projects potentially helped avoid/delay entry to long-stay residential care for many of these individuals, with an associated potential for significant cost savings. The demonstrable quality of life and subjective wellbeing gains provide a substantial and crucial addition to the value and value-for-money case. In their own right, these gains for persons with dementia and family carers represent considerable value for the dementia care system, even before taking into account the potential long-stay residential care cost savings. From a resource allocation perspective, a relatively small percentage increment in the standard allocation of social care supports for dementia care could enable provision of additional, personalised supports for a substantial number of persons with dementia and their family carers in each HSE area.

Conclusions

There is a demonstrated and compelling value case for provision of personalised and person-centred supports as part of community-based care for people with dementia in Ireland. This is underpinned by an extensive range of evidence from the projects and from the wider research literature. The incremental costs, over and above standard care costs, are relatively small and represent good value for money in delivering on dementia policy and the National Dementia Strategy. In addition, there is the potential for substantial savings from delay or avoidance of long-stay residential care costs.

The evidence presented in this report indicates a strong case for resourcing the provision of personalised supports across the trajectory of dementia, with the types of lower intensity and personalised supports provided by these projects having particular relevance. These can be scaled to respond as individual need increases. This approach could reach large numbers of people with dementia and family carers, particularly at an earlier stage. The projects show that it is practically feasible to implement these types of services at local level within HSE community care services. The basic model could be replicated in every area across the country, whilst allowing for tailoring and fine-tuning to local needs and capacities.

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