LIVERPOOL JOHN MOORES UNIVERSITY
CENTRE FOR COLLABORATIVE INNOVATION IN DEMENTIA

Dementia Reablement Service

An Evaluation for Cheshire East Council

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“ In such a short time

You have changed my mind

The advice you have given

Has made our lives worth living

That smiling face

Will keep us at the right pace

To enjoy our lives together

For ever and ever ”

(DRS User)

Contents

EXECUTIVE SUMMARY

The evidence from this evaluation suggests that the Dementia Reablement Service is providing a high quality time limited intervention for some of the most vulnerable people in Cheshire East. It has successfully arrested decline and provided a stabilising effect on general sense of wellbeing and overall quality of life. There is indeed overwhelming evidence that service users and carers feel more confident about remaining independent for longer at home while also feeling informed about future options. Professionals too were unanimous in their praise for the service highlighting ease of referral, integrated working and linking otherwise disparate services together. Perhaps most importantly in-depth qualitative interviews demonstrated a wide range of person centred practice that is transforming lives, often quite dramatically. As might be expected, there have been one or two teething problems but these can be easily addressed to ensure a consistently excellent service. However, the grassroots commitment to the service that is evident in this report needs to be matched with a commensurate investment in community resources so that improvements in health and wellbeing can be sustained and independently maintained by service users and their families in the future.

INTRODUCTION

Tackling dementia is one of the greatest challenges facing the UK today, and it is getting greater every day. There are currently about 850,000 people with dementia living in the UK and, while there is some debate over the numbers, according the most recent Dementia UK (November 2014) report:

> *If the prevalence of dementia remains the same, the number of people with dementia in the UK is forecast to increase to 1,142,677 by 2025 and 2,092,945 by 2051, an increase of 40% over the next 12 years and of 157% over the next 38 years.*

The perceived economic 'burden' on future generations threatens to prejudice public attitudes (and potentially diminish the quality of care and support provided) but the majority of this cost (currently estimated at £26 billion) is in fact met by carers, families and people with dementia themselves. Caring for people with dementia is everybody's responsibility and it is incumbent on the whole of society, from the top down, to respond humanely to the needs of our growing, aging population.

In the *Prime Minister's Challenge on Dementia* (DH 26 March 2012) David Cameron promised to go 'further and faster' in developing improvements in dementia care. However, progress has been slow and major barriers remain including the need for people to receive a timely diagnosis, reducing stigma by increasing understanding and awareness across society, and building national capacity and capability in dementia research (Department of Health, 2013). Perhaps most importantly, as the Alzheimer's Society Dementia 2013 report highlights, 'health and care for people with dementia still needs improving'.

It is not therefore just about finding a cure but finding a way to live well as individuals, families and communities affected by the condition. Clearly many resources are needed but the creation of integrated personalised care plans, support for carers, dementia friendly communities and greater awareness have all been highlighted as government priorities aimed at enabling people with dementia to live well.

The Prime Minister's Second '2020' Challenge (Department of Health 2015) outlined David Cameron's desire for the UK to become 'the best country in the world for dementia care and support and for people with dementia, their carers and families to live'. Achieving this requires 'Every person diagnosed with dementia having meaningful care following their diagnosis, which supports them and those around them' (Department of Health 2015 p.6). This may involve, it is suggested, receiving information on what post-diagnosis services are available, access to relevant advice and support, and making carers aware of, and offering, opportunities for respite, education, training, emotional and psychological support.

It is against this backdrop of national concern that the Dementia Reablement Service (DRS) was set up, however, there are pressing local concerns too. Cheshire East has the highest percentage of over 65s in England, of whom almost 6000 people are thought to have dementia (www.cheshireeast.gov.uk). The vast majority of these continue to live at home yet few receive the advice and support necessary to do so safely and independently. In April 2015 Cheshire East Council therefore launched the DRS to provide flexible, intensive support to individuals and their families and carers who are living with early stage dementia. Its vision is to help people with dementia to live independently for as long as possible and delay the need for formal care services (including, for example, avoidable admissions to hospital). The DRS is a low-level limited-term service (lasting up to 12 weeks) providing people living with dementia (PLWD) with a dedicated support worker. According to the Vision Statement the Support Worker will:

- Work flexibly to Identify what is important to PLWD/families and to deliver;
- Work with PLWD to create a personalised plan to support them to live independently, to continue with social activities and to access new opportunities;
- Share with PLWD creative, practical tools to give them the confidence to take control of their lives;
- Support PLWD and their carers to take control of their care and support and empower them to plan for the future effectively.

In short, the DRS provides flexible, intensive support to individuals and their families and carers who are living with early stage dementia, enabling them to continue doing what they have always done independently and for as long as possible. Specific outcomes for the service are as follows:

- PLWD feel that they will be able to look after themselves and retain their independence for longer

- Families and carers of PLWD will be supported and reassured that their family member can safely live independently
- PLWD will be empowered and confident to live independently
- Social isolation will be reduced for PLWD, and their carers
- PLWD can choose and have easy access to the type of support they need, when they need it
- Delaying the need for formal social care interventions e.g. residential/ nursing care and preventing the need for crisis interventions and support e.g. Social Care Emergency Duty, GP Emergency Out of Hours and Non Elective Hospital Admissions;
- PLWD and their carers feel more informed about their options for the future;
- PLWD and their carers feel they have a good quality of life.

BACKGROUND

The general public is often fearful of engaging with people living with dementia so interaction can be awkward or, worse still, non-existent because it is assumed 'they just live in their own little world'. It is perhaps unsurprising then that the Alzheimer's Society Dementia 2014 survey reported that 40 per cent of people with dementia feel lonely and 34 per cent do not feel part of their community. The consequences of this are far reaching, as evidence strongly links loneliness and isolation with a range of poor health and wellbeing outcomes including depression, irritation, self-neglect and rapid decline (Holwerda et al., 2014; Alzheimer's Society 2013).

The agitation, hostility and physical aggression that often results are often regarded as 'challenging' or 'problematic' by professionals and unless addressed may lead to further exclusion, poor quality of life, depersonalisation, unmet needs, and a reduced sense of identity (Downs & Collins 2015). Families and carers therefore report widespread dissatisfaction with the care and support they receive (Jurgens et al 2012) while they themselves suffer from frustration, anger and guilt (Large & Slinger, 2015).

The evidence above suggests the real possibility of many people with dementia becoming locked into a spiralling cycle of isolation and deterioration. While perhaps not inevitable the consequences of such a scenario for many are likely to be far reaching as both opportunity and capacity for living well with dementia diminish. More optimistically, what the isolation-deterioration hypothesis also seems to be suggesting is that the depression, irritation, self-neglect and rapid decline often associated with dementia is potentially avoidable with appropriate early intervention. Indeed providing people with dementia with skills, resources and positive support are increasingly recognised as empowering and protecting them from decline (Fratiglioni et al. 2000; Crooks et al. 2008; Nomura et al 2009).

EVALUATION

Liverpool John Moores University's *Centre for Collaborative Innovation in Dementia* was commissioned by Cheshire East Council to try and establish whether these aims and objectives of the DRS have been achieved. The Centre hosts Innovate Dementia which provided the expertise in participatory research and evaluation underpinning implementation over two overlapping phases. The initial service development phase (pre-evaluation) focussed on understanding the real life needs of the service (through Action Learning and SURF groups) while the second phase (evaluation) explored and established impact.

METHODOLOGY

This was an embedded participatory evaluation that required full organisational commitment and service user participation. Preliminary discussions with DRS Commissioners and managers identified broad baseline and outcome measures based on the DRS objectives and existing literature. These were then formalised and incorporated into the DRS assessment tool (Information and Support Plan) and revised further in the light of feedback from frontline workers.

Capacity building is central to participatory evaluation so DRS workers/managers attended an initial workshop (facilitated by Liverpool John Moores University). The group then met regularly (once a month over 6 months) to explore, evaluate and validate emerging findings. Using the DRS team as an action learning set additionally enabled the development and testing of new and existing ideas, innovations and interventions. DG facilitated the groups and provided activities for participants to reflect on what works, what does not work and what needs to be done differently. Additional support on how to best capture evidence of change was also provided. These discussions were audio recorded and any artefacts produced (e.g. notes on tables) along with personal notes taken (by DG) added to the evidence base. The core (quantitative) data was collected by DRS workers themselves at the beginning of the intervention (to establish baseline measures) and again at the end (to capture change). Service users were given opportunity to opt out of the evaluation at both points.

It is now generally regarded as good practice to involve service users in the evaluation and development of services (Litherland & Capstick, 2014). However, many assume that people with dementia lack the will, desire or capacity and so provide them with no opportunity to participate. As a result, their opinions and experiences are routinely excluded from knowledge creation, innovation and service development (McLaughlin, 2010; McKeown et al., 2010). In order to maintain the ethos of the DRS in promoting the citizenship of people with dementia it was imperative that this evaluation engaged directly with recipients of the intervention. Service users who opted in to the evaluation were asked if they would be prepared to participate further.

While service user participation was deemed central to this evaluation, great caution was exercised, especially as interviews can be emotionally demanding and without obvious benefit (McLaughlin, 2010; Tanner, 2013). Any DRS users deemed vulnerable, unwell, unstable or lacking capacity were therefore not invited to participate while those who were invited were fully informed of the purpose of the interviews and their right to refuse or withdraw at any time. They were also offered the choice of being interviewed alone or with support from carers and / or DRS support workers. As with Tanner's (2013) study, for those who did participate, there was a clear desire to speak out, help others and improve services.

In brief, the evaluation generated data from a variety of sources including both qualitative and quantitative measures, including:

- Baseline data: Standard measures of quality of life and social functioning were collected by DRS workers at the beginning and end of the service provision along with narrative summaries.
- Information and Support Plans: Anonymised data from Support Plans was collated and analysed.
- Team Performance: Anonymous statistical data was collected by DRS administrators including diagnoses, referral routes, and contact hours.
- Monthly action learning sets: DRS workers explored and documented progress and impact of the service. Barriers to change and challenges were also be considered along with plans to overcome them. This formative process provided necessary background information, fed into service development and informed data collection.
- User Interviews: 11 purposefully selected service users were interviewed by DG after intervention. Interviews were open ended with occasional prompts from their Information & Support Plans when necessary.
- Professional Interviews: 13 interviews were undertaken with a range of dementia specialists including consultant physicians, senior managers and frontline professionals. These focussed on working relationships with the DRS and were again open ended asking: What has worked well? What has not worked well? What could be improved?
- Additional Feedback: The DRS routinely requested feedback from participants which, along with spontaneous 'compliments', was analysed for common themes.

FINDINGS

Demographic and Contact Details

Over a period of 10 months (May 2015 – February 2016) there were a total of 513 referrals to the service: 285 in the North and 228 in the South of the region. The majority of these

came through the Memory Clinics (58%) while other significant referrers included Skilled Multi-Agency Response Teams (adult social care frontline services) (12%) and families / carers (9%). Unsurprisingly, and in-keeping with the age spread of dementia nationally, most referrals (81.7%) were over 75 years of age. Type and duration of contact was also recorded for this period and data shows that there were a total of 2664 face to face interactions with service users (home visits or accompanied visits) amounting to over 2911 hours of contact. In addition to this, 760 hours of telephone calls to (and research on behalf of) the user/carer/family were recorded over 3332 events. Among the most frequently undertaken tasks were help to access daytime opportunities and activities (91 events), financial and Power of Attorney (87 events), and carer's information (81 events). However, the range of interventions was varied and included help and/or advice with the following:

- Accompanied visit for personal care appointments
- Advocacy for service user to attend appointments
- Apps (e.g. Remind Me)
- Arranging personal care
- Assistive Technology (e.g. equipment, tablet devices) / telehealth
- Befriending Services
- Brain training exercises
- Carers information
- Dancing classes
- Daytime Opportunities and Activities
- Dementia awareness
- Dementia cafés
- Design and environment
- End of Life information
- Exercise classes
- Expressive arts
- Financial help and Power of Attorney
- Health awareness and Advice
- Home Improvement Gardening Cleaning
- Housing
- Meals on Wheels
- Medication Assistance
- Memory suitcase or box / Memory Tree
- OT
- Other Agencies Support
- Self-help strategies (e.g. Photographs to locate items, prompt cards)
- Referral for a Social Care / Carers Assessment
- Singing for the Brain

- Sitting Service
- Support groups such as the Dementia Together Group
- Telephone Help Lines
- Using transport or attending travel training
- Voluntary work
- Social media for networking / websites

While work undertaken by teams in the North and South was roughly comparable it is worth noting some differences in the nature and processing of referrals. In addition to dealing with a larger volume of referrals (as noted above), service users also tended to be further along the dementia clinical pathway in the North, almost twelve months 'post diagnosis' on average. This may be contrasted with five months in the South Team. 94% of referrals to the North Team were contacted within one week while in the South the figure was 64%. The Average wait between first contact and initial visit in the South Team was just under two weeks while in the North it was more like a month. Indeed, more than half of the service users had to wait over a month before being visited. Once undertaken, however, the vast majority of interventions (87%) were completed within three months. This figure was lower in the South Team (68%) which also spent considerably more time in face to face contact. It is of course impossible to surmise the complexity and quality of work from these figures but there is clearly a greater volume of work being managed more quickly in the North (once intervention is initiated) while in the South fewer and longer interventions with more direct contact are taking place.

Referral Volume

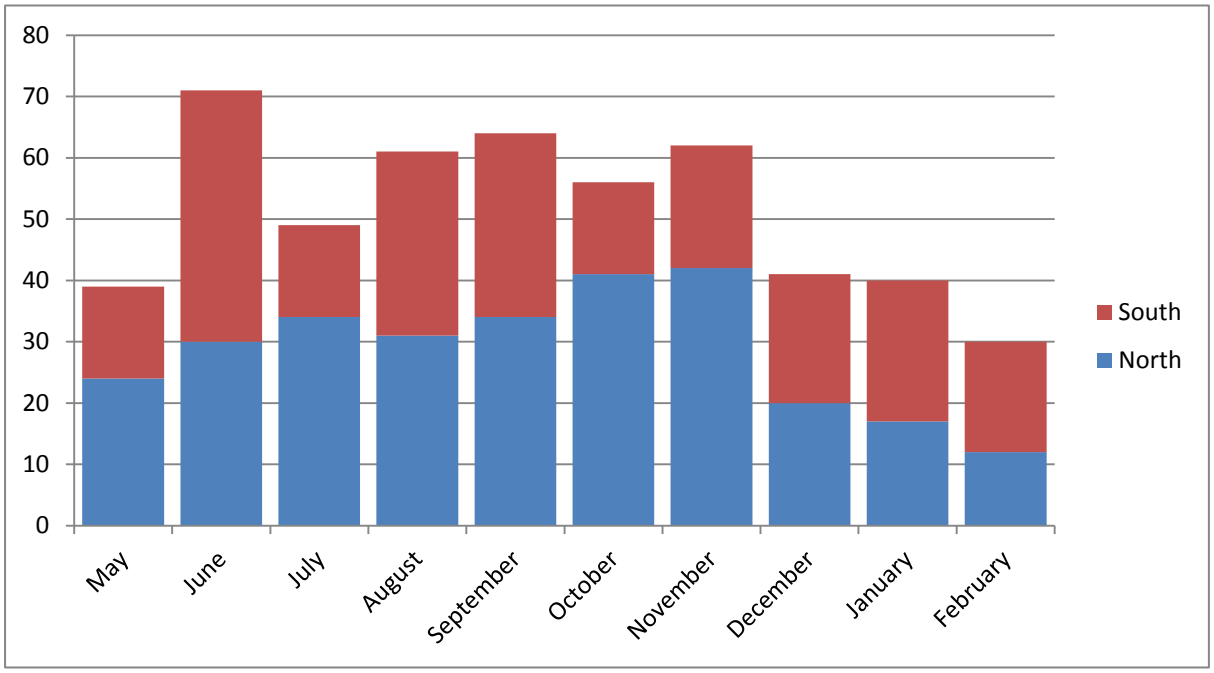


Figure 1

Referral Routes

Source	North	South	Total	%
Memory Clinic	147	152	299	58%
GP	15	7	22	4%
Dementia Advisor	1	8	9	2%
OT	2	7	9	2%
Self-referral	2	5	7	1%
SALT	14	0	14	3%
SMART	33	28	61	12%
Other eg Age UK, Community Agents, Community Matrons	33	15	48	9%
Family/Carer	38	6	44	9%
Unknown	0	0	0	0%
Total	285	228	513	100%

Figure 2

Age Profile of Service Users (age at referral date)

Age range	North	South	Total	%
under 54	0	2	2	0.4%
55 - 64	6	10	16	3.1%
65 - 74	38	38	76	14.8%
75 - 84	136	120	256	49.9%
over 85	105	58	163	31.8%
Unknown	0	0	0	0.0%
Total	285	228	513	100%

Figure 3

Contact Type

Contact Type		North	South	Total
Telephone calls (and research) to and on behalf of the client/carer/family	No. of	2328	1004	3332
	Time Spent on (hrs)	446h 40m	313h 32 m	760h 12m
Home Visits	No. of	728	748	1476
	Time Spent on (hrs)	890h 58m	1264h 5m	2155h 3m
Accompanied Visits	No. of	510	678	1188
	Time Spent on (hrs)	353h 0m	403h 35m	756h 35m
Total Contact Time	Time (hrs)	1690h 38m	1981 h 12m	3671h 50m

Figure 4

Time between First Contact and Initial Visit

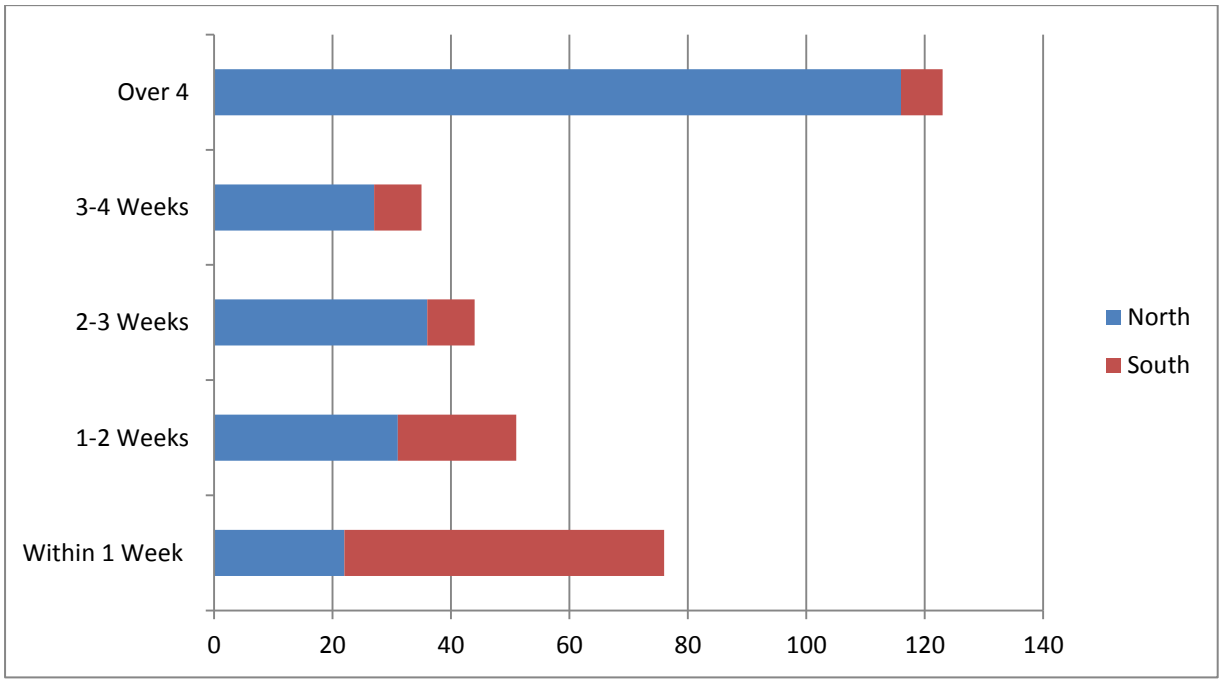


Figure 5

Quantitative Data

Diagnosis impacts on every aspect of health and wellbeing: from the performance of daily activities to personal happiness, independence, confidence and sociability. Improved quality of life (QoL) is therefore one way of gauging an interventions' effectiveness. This was measured using an amended version of DEMQOL (Smith et al, 2005) - a validated tool for

capturing health related quality of life. Pre and post measures were gathered by DRS workers before and after intervention.

DEMQOL is described by its developers as a 'bottom-up' measure but it is based on topics from existing research e.g. a predetermined checklist of topics derived from the literature, which would have constrained the breadth of measures and emerging themes and therefore needed adapting and supplementing for the purposes of this evaluation. Despite these limits DEMQOL remains one of the best measures of HRQOL for people with mild to moderate dementia. The instrument includes 29 individual measures but this would have been too onerous in the context of this intervention and evaluation so a DEMQOL 'light' version was developed focussing on: enjoying life, confidence to live independently, feeling lonely, worry about not having enough company, worry about getting help when needed, and overall quality of life. This was supplemented with a range of intervention specific questions.

Quality of Life: Service Users

The charts below represent *change* in 'pre' and 'post' measures over the intervention period. Green represents positive change, red represents negative change and blue represents no change.

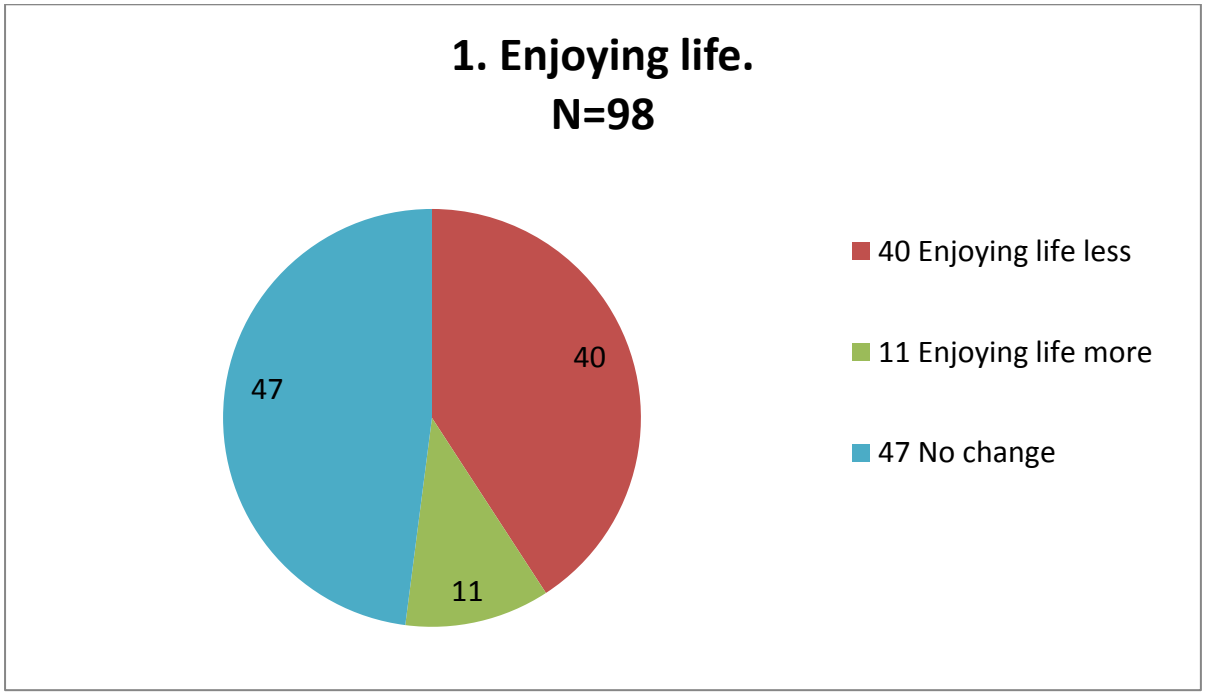
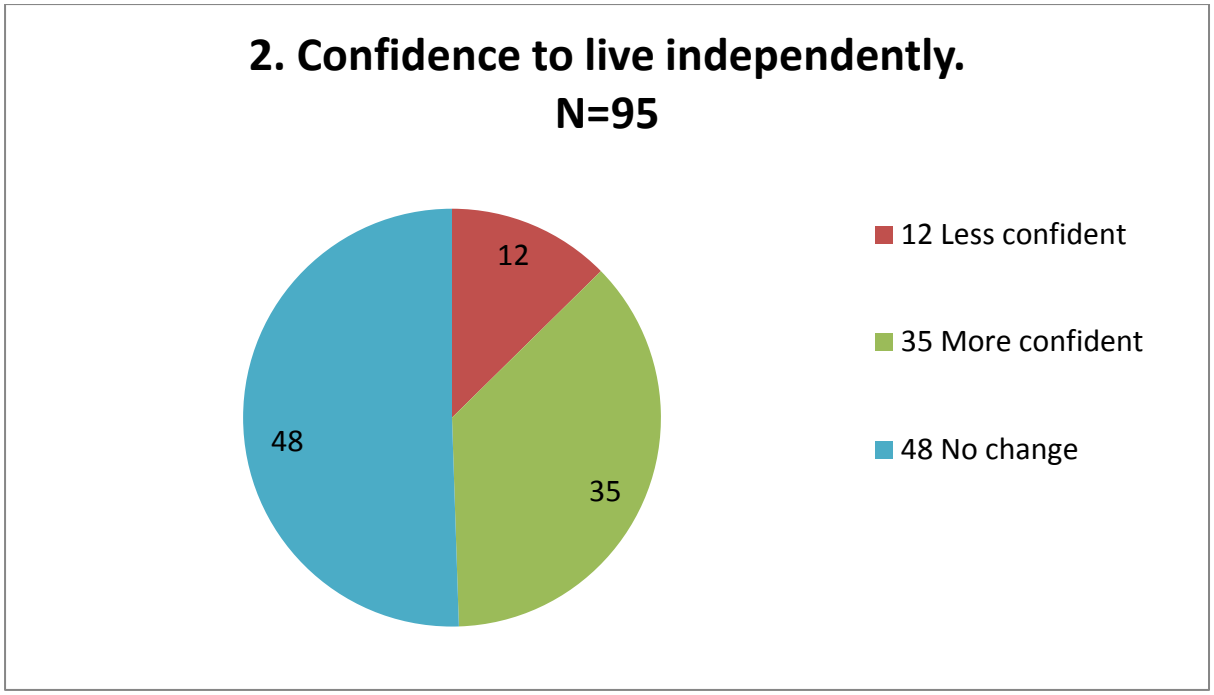


Figure 6



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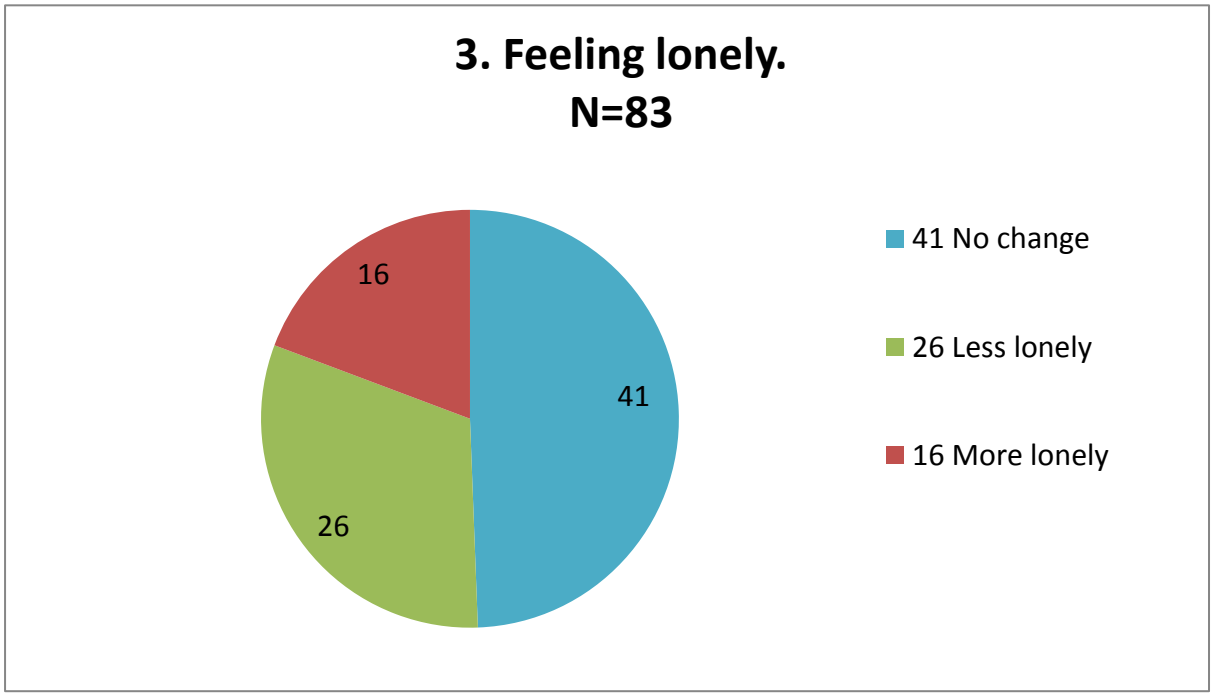

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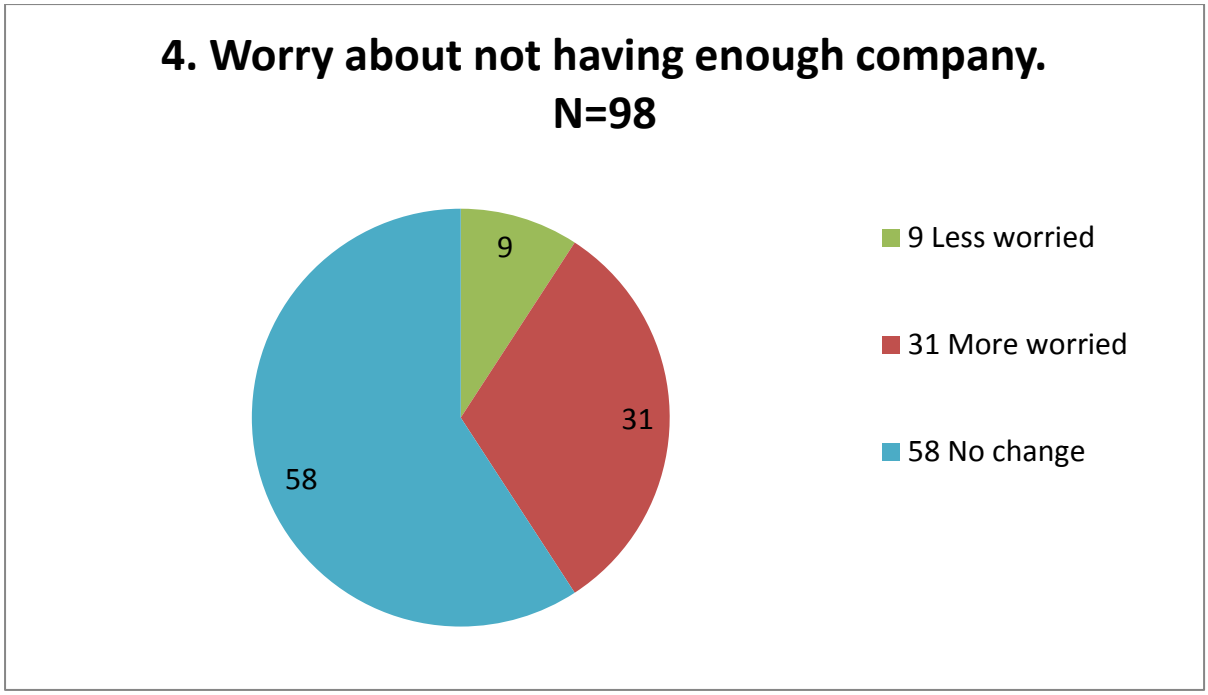


Figure 9

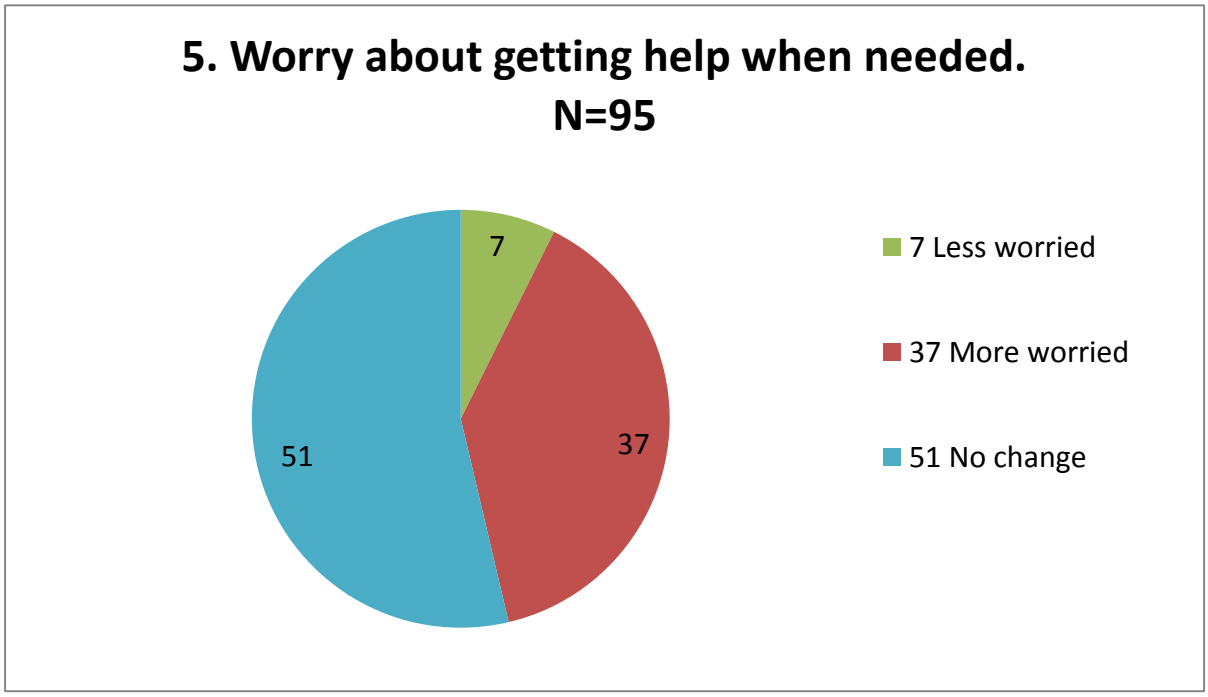


Figure 10

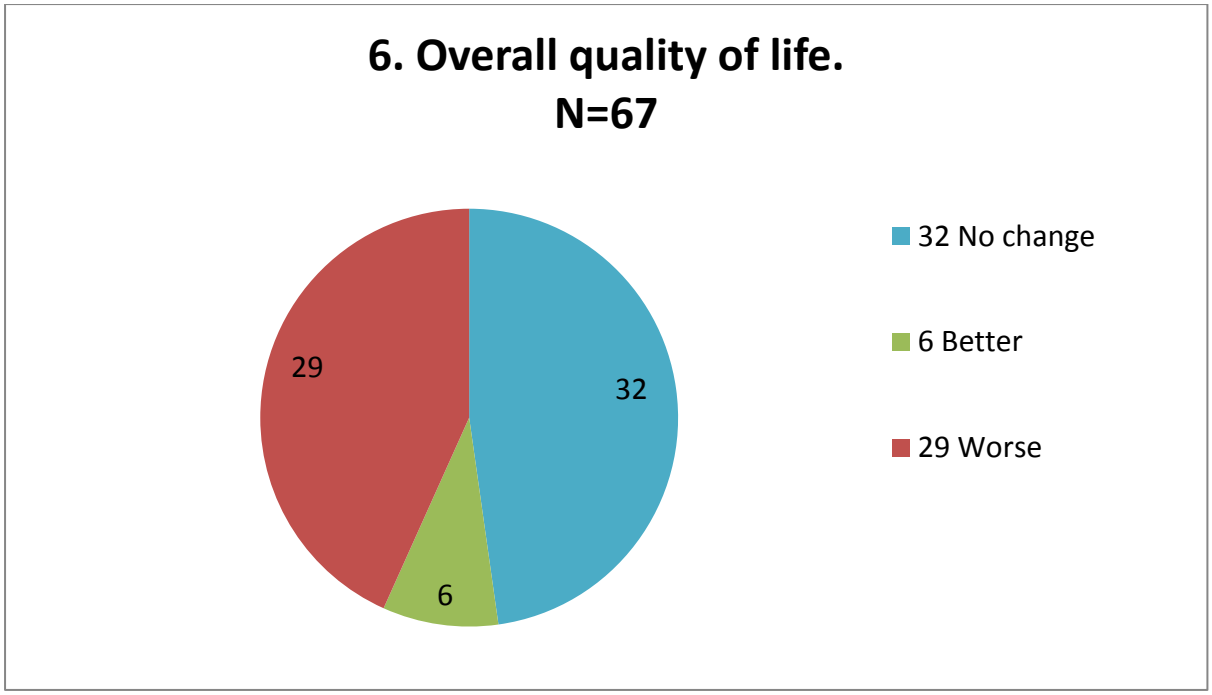


Figure 11

Quality of Life: Carers

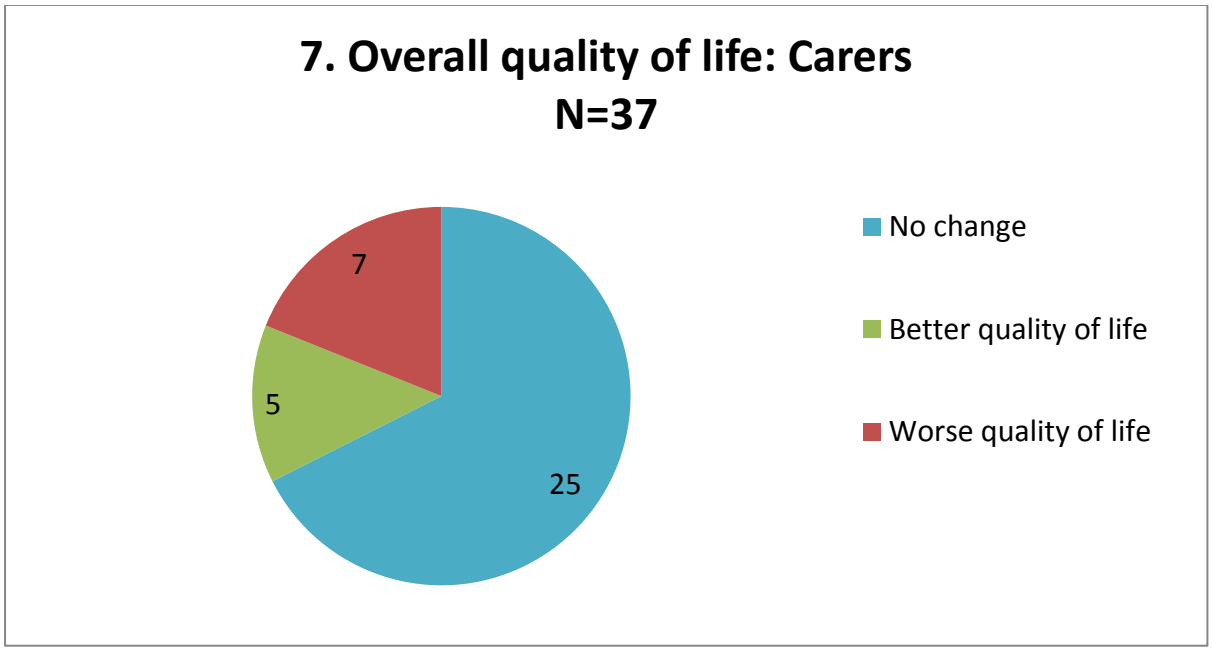


Figure 12

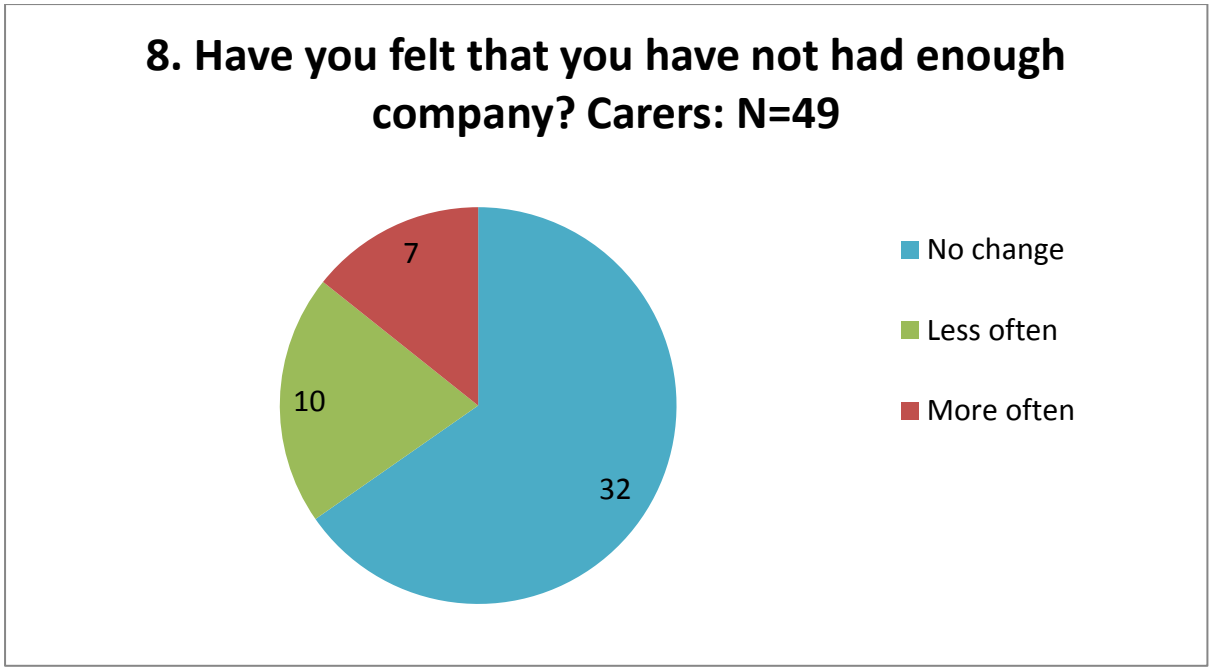


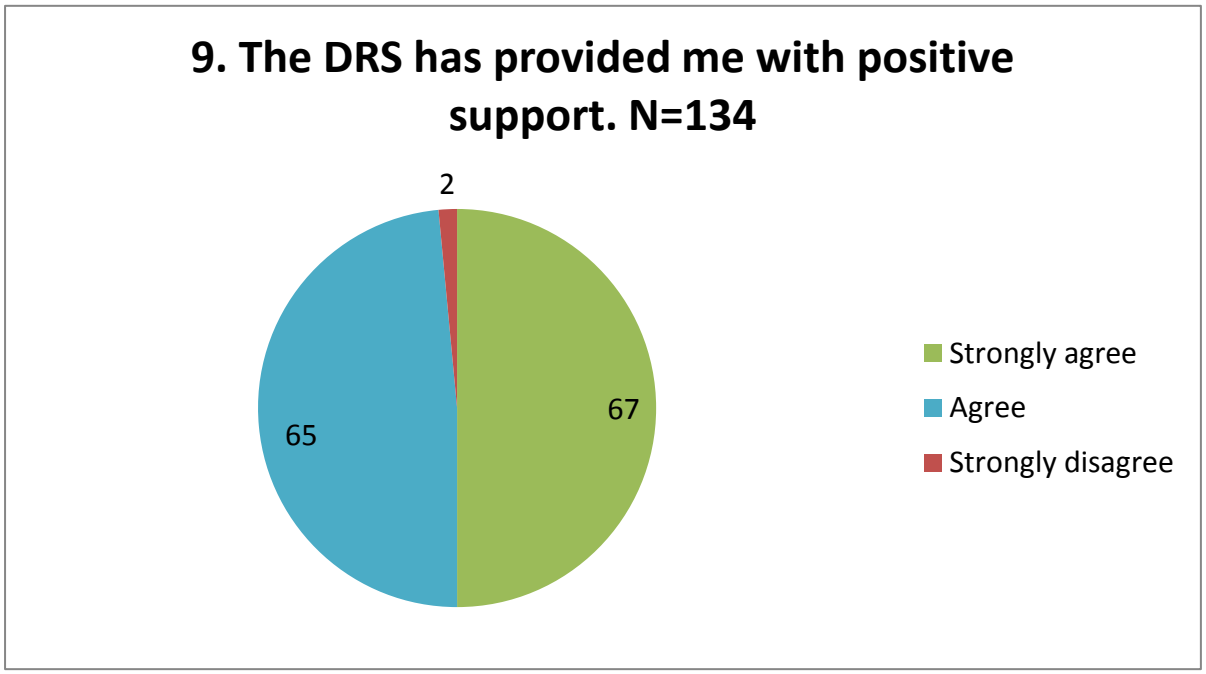
Figure 13

Although the amount of positive change seen in the DEMQOL outcomes *appears* modest, for both carers and service users, these findings are consistent with other reports of the benefits of early-stage interventions which have shown 'no change' (Camic et al 2013; Borbasi et al 2011) or modest non-significant improvements when compared to declining quality of life in control groups (Logsdon et al 2010; Marshall et al 2015). Without a control group it is impossible to be certain but it seems highly likely that the DRS has indeed helped to arrest decline and perhaps stabilise the quality of life of recipients of the intervention. That is to say, without intervention, decreases in quality of life would not have been unexpected for people living with dementia and their carers following diagnosis (see also Camic et al 2013).

Intervention Specific Outcomes

In addition to DEMQOL questions, participants were asked specific questions about the DRS intervention. This focussed on the effectiveness of the support plans implemented and preparation for the future. This was supplemented further with a brief narrative summary at the initial and final meeting with DRS workers.

Intervention: Service Users



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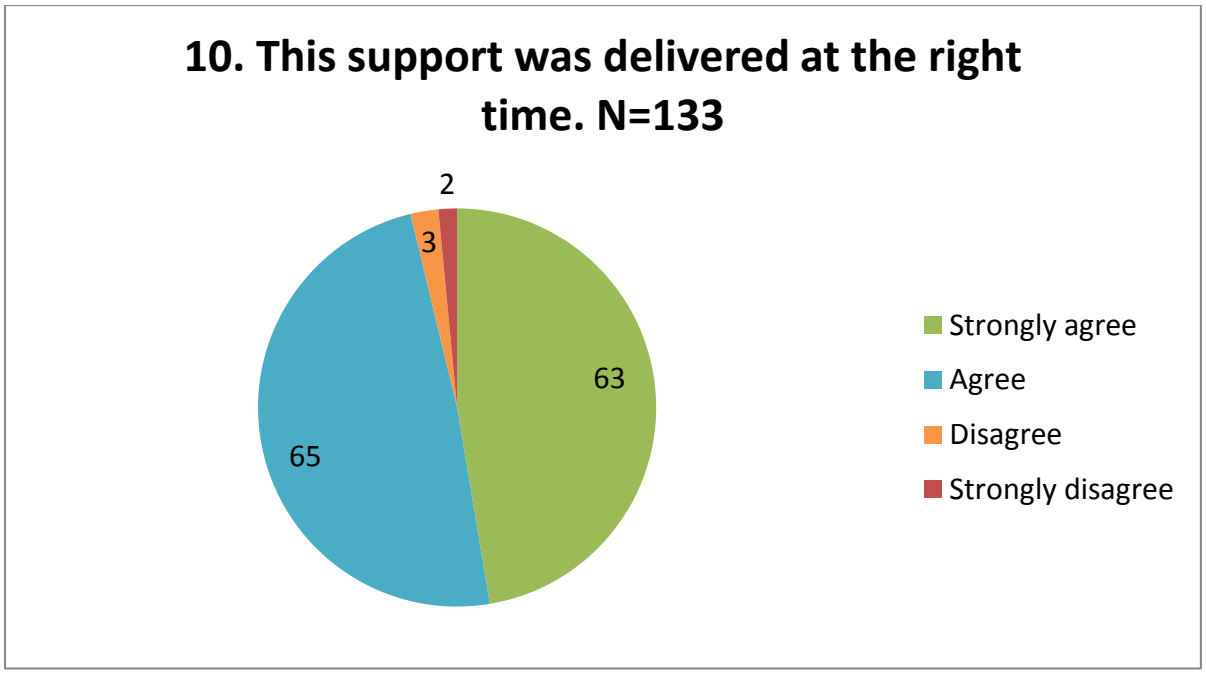

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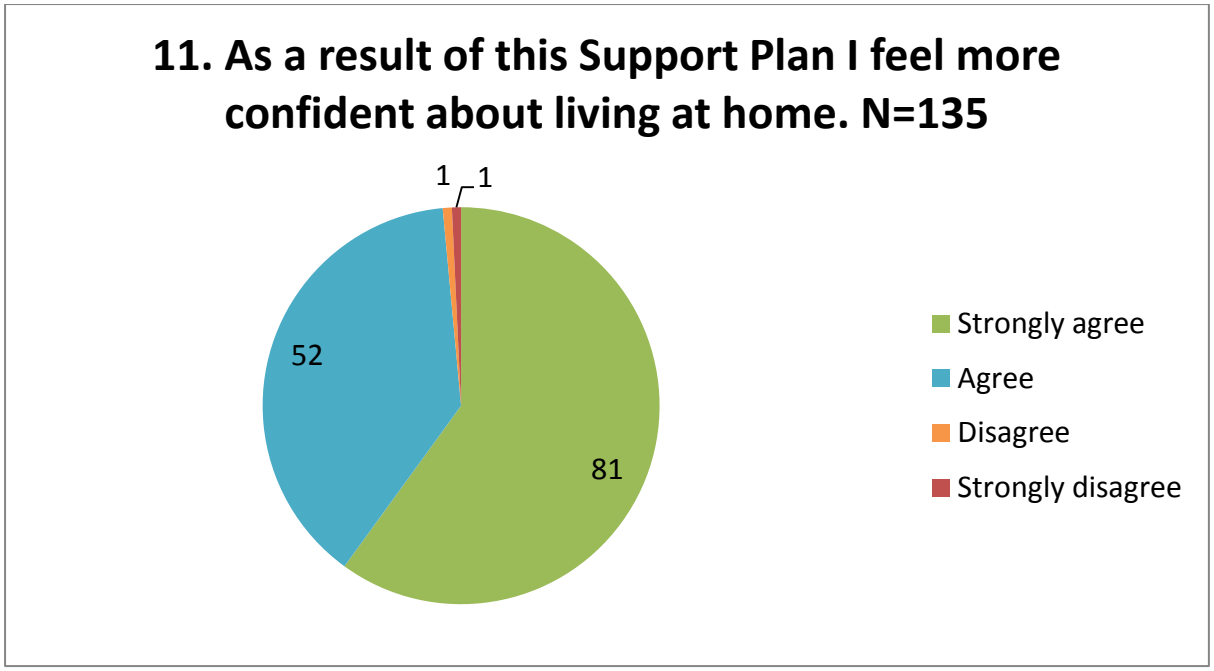

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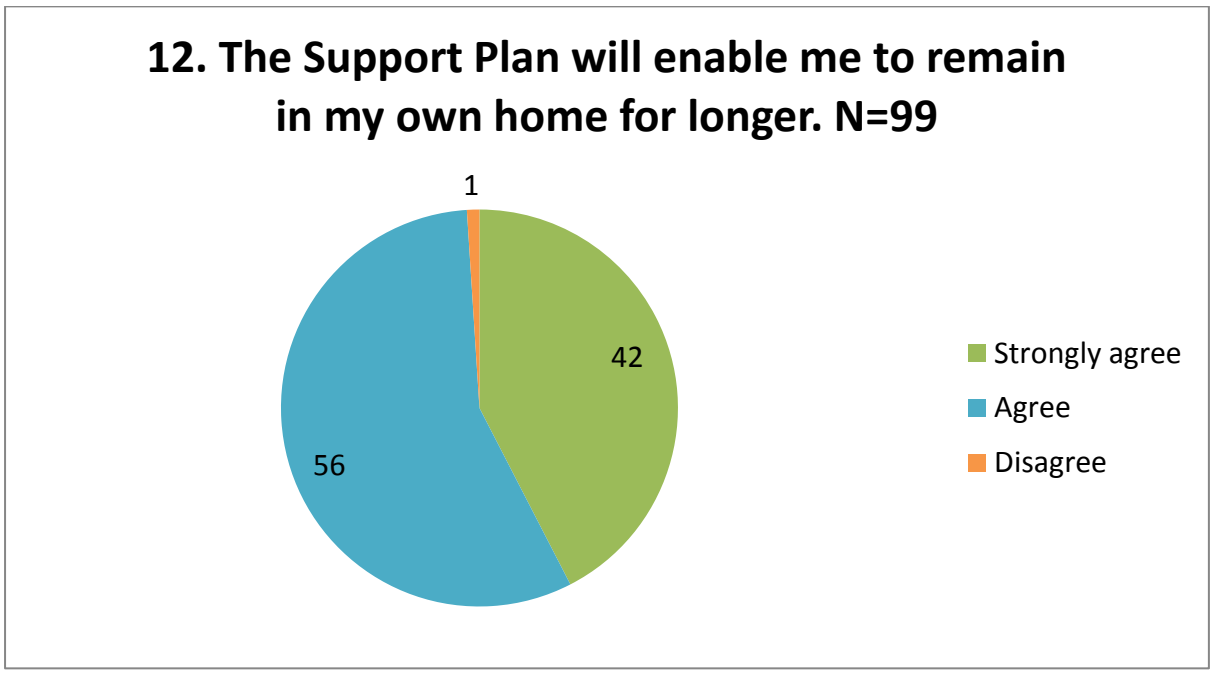

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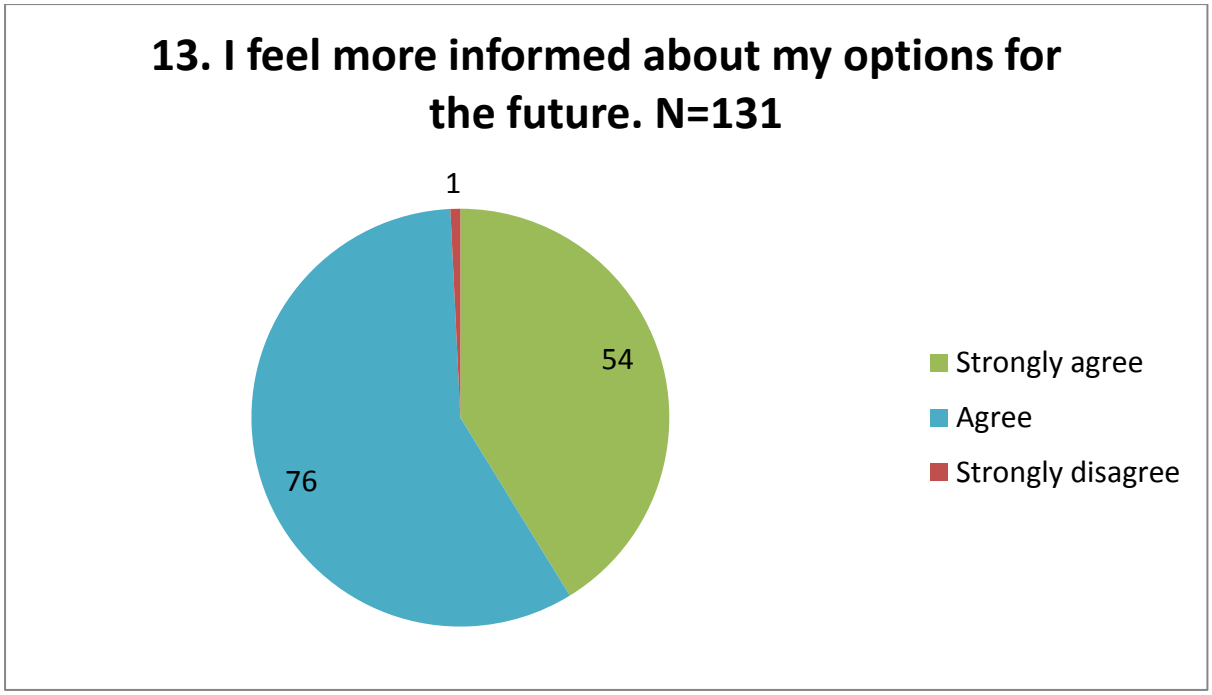
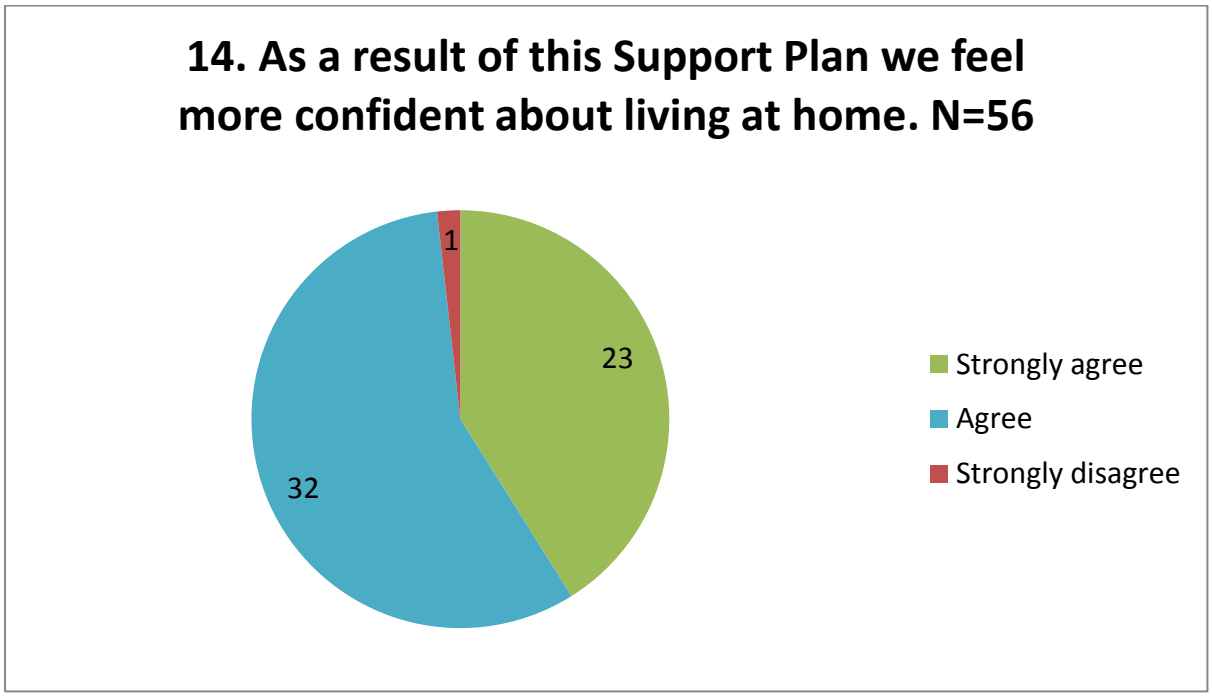


Figure 18

Intervention: Carers



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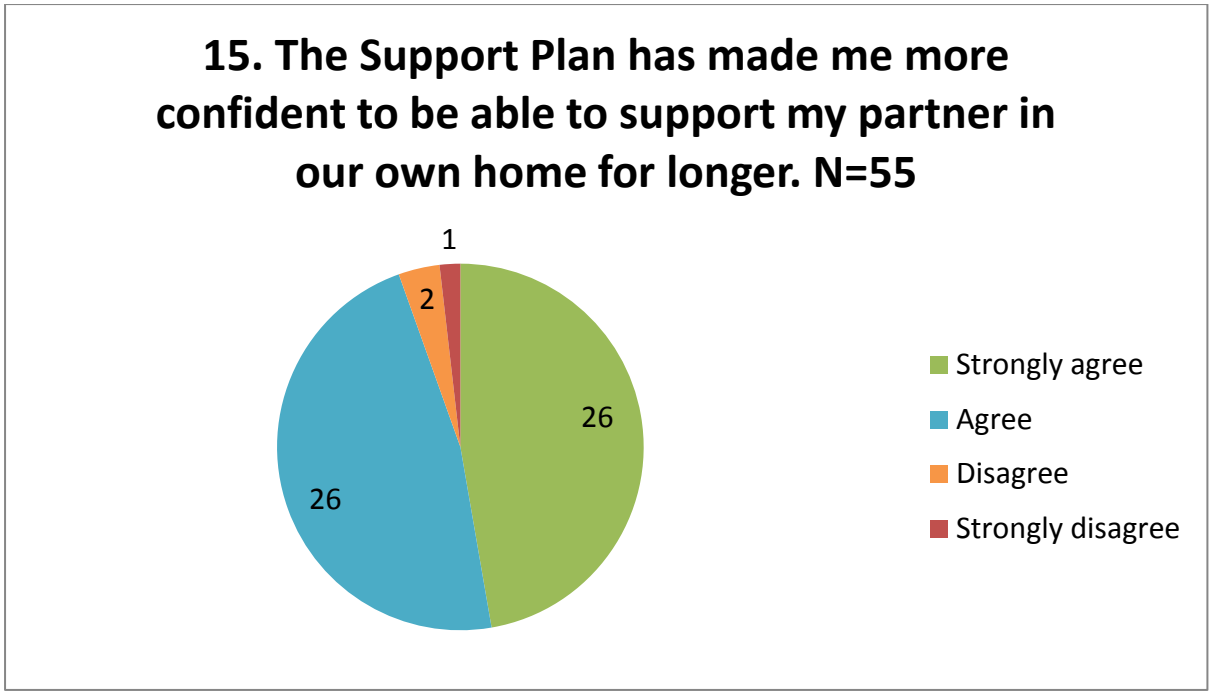

Figure 20

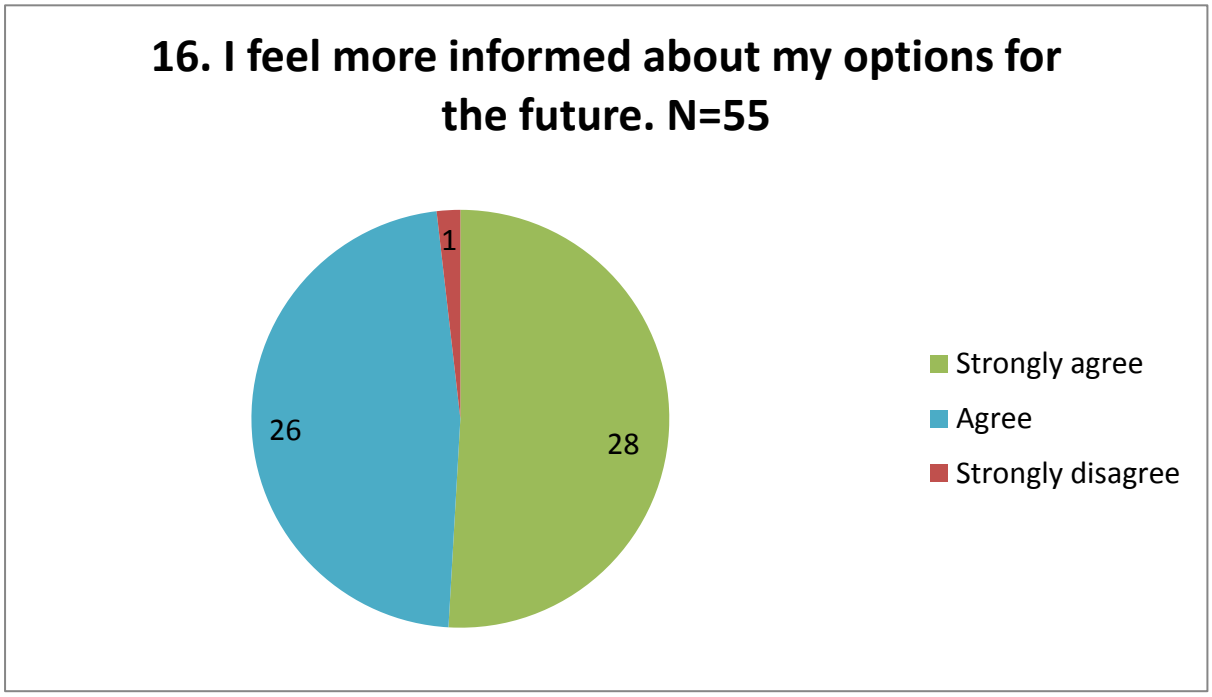

Figure 21

While DEMQOL questions indicate stability, these intervention-specific responses were overwhelmingly positive, demonstrating beyond question that specific DRS targets are being achieved successfully. Support Plans are not only timely but also positive – providing recipients with the confidence needed to remain independent and safe at home for longer. Brief qualitative data collected in 74 narrative summaries supports this, highlighting social increased activity in particular, as one service user is recorded stating: 'I like to go to the

lunch club now which I didn't think I would, the food isn't always good but I enjoy the company'. Being able to remember medication also featured highly along with safety measures and knowing where to go for help if needed in future. Indeed, it is possible to be still more specific as after completing the intervention DRS users were asked to evaluate the impact of all the interventions they received. These were recorded in their Information & Support Plan and collated and summarised as follows:

Intervention Specific Impact

Intervention / Impact	What difference did the support make?					
	A lot	Quite a lot	A little	None	Blank	Grand Total
Accompanied visit for personal care appointments	6					6
Advocacy for service user to attend appointments	1					1
Apps	6					6
Arranging personal care	21					21
AT	55	2	2	1		60
Befriending Services	34		3		3	40
Brain training exercises	1					1
Carers information	72	2	7			81
Dancing classes	4					4
Daytime Opportunities and Activities	82	7	2			91
Dementia awareness	15	1	1			17
Dementia cafés	43	1	2			46
Design and environment	5					5
End of Life information	1					1
Exercise classes	25	1	1			27
Expressive arts	7		1			8
Financial help and Power of Attorney	77	8			2	87
Health awareness and Advice	15					15
Home Improvement Gardening Cleaning	11					11
Housing	1					1
Meals on Wheels	21	1	1	1	1	25
Medication Assistance	5					5
Memory suitcase or box	9		1			10
Memory Tree	4					4
OT	16	1			1	18
Other Agencies Support	16		1		1	18
Photographs to locate items	1					1
Post it notes and Laminated Telephone Lists	2					2
Prompt cards	2					2
Referral for a Carers Assessment	10					10

Referral for Social Care Assessment	19					19
Singing for the Brain	8		1			9
Sitting Service	2					2
Support groups such as the Dementia Together Group	8		2			10
Telephone Help Lines	4		1			5
Using transport or attending travel training	36	3			2	41
Voluntary work	2		1			3
(blank)	1	1				2
Grand Total	**648**	**28**	**27**	**2**	**10**	**715**

Figure 22

The positive evaluation of a wide range of interventions (above) not only suggests flexible person-centred practice but also *effective* practice. Priorities for DRS users include accessing daytime opportunities and activities, financial help and Power of Attorney, assistive technology, and carers' information.

Qualitative Data

It is important to remember that the DRS service offers a person centred approach which means that service users themselves determine what the key issues are that need to be addressed (e.g. social isolation or remembering tablets) and the level of intervention (e.g. signposting, information or accompanied visits). Not everyone therefore registered change in the same areas of need. This means that in order to present a complete picture the evaluation required a broad approach utilising open-ended qualitative methods that could accommodate the indeterminate field of person-centred practice. To exemplify this crucial aspect of the DRS a further four real-life case studies were prepared by support workers (see Appendix 1) illustrating the range and variety of person-centred intervention undertaken along with interviews with service users and professionals.

Interviews with Service Users

Rather than breaking down service user interviews into constituent parts, analysis focussed on the overall narrative performance, highlighting the turning points and impact the DRS had on living with dementia. As Mrs A notes (below) 'It's difficult to quantify these things' so this holistic approach seeks to capture the meaning of intervention from the point of view of interviewees rather than standardised indicators of change.

Building a Relationship: Mrs A

Highly educated, independent and sociable Mrs A continues to attend several professional clubs but has had to stop playing Bridge because she can no longer keep score. She has no family to speak of. Like several participants, Mrs A spoke of a transformation in her relationship with her DRS worker. She was initially deeply sceptical but reluctantly agreed to go for a coffee (but still thinking 'what a waste of time and money'), 'I can't drive and can't walk very far but the paper shop is near the coffee shop and I asked 'can I pay my bill?'' This

simple request belied a basic need for an erudite academic and avid consumer of news: paying her paper bill. More importantly, it opened the door for a deeper and transformative engagement. Mrs A described many visits, advice and practical helps that followed 'from the profound to the mundane and everything in between' she laughed. This included, accompanied hospital visits, appointments at the Citizen's Advice Bureau (regarding Attendance Allowance) and information about care homes. Most importantly Mrs A was recently widowed and does not wish to continue living. She has also been diagnosed with cancer and does not want treatment (the DRS worker helped identify equipment to enable emergency services to be aware that a DNR is in place). Whether helping with end of life choices or visiting a mobility scooter shop, Mrs A was deeply grateful to the support worker for helping her with 'things I hadn't even thought about'. Without DRS intervention, she concluded:

> ***'I'd have had less time, less pleasure, made mistakes*** [provides example of help choosing an appropriate calendar]... ***It's difficult to quantify these things but these things come to mind'***

Building Social Networks: Mr B

Mr B and his wife have no local family. He used to paint and was previously very active. Now, with early stage dementia, he enjoys doing crosswords. The couple received practical advice and help with benefits and accessing public and volunteer transport for appointments. Most important, however, were the support groups:

> ***'It's got him out for a start. We can't drive, so where would he go? And all the help that's available, that we wouldn't have heard about if we hadn't gone to these meetings. The people there were really helpful'***

The DRS is not just about providing practical support, but also linking people with the wider community. For Mr and Mrs B, one group led to another and they are 'more confident about the future knowing there is so much out there'. The DRS was not providing this support but, Mrs B concluded, 'If it wasn't for [DRS support worker] we wouldn't have known about any of this'.

Filling the Gaps: Mr C

Mr C used to be a research chemist but was made redundant. With the money he made he bought a cycle shop which his son now runs, though Mr C still helps out despite his dementia. He and his wife have a supportive family and are self-reliant. They described a very successful low-level early intervention that provided future oriented advice and support. Mr and Mrs C have always lived very active lives and while this has clearly slowed down they continue to be 'busy'. They love walking and, they recalled, 'she even came up with walks we could go on!' The DRS intervention therefore mostly involved information (about dementia and support groups) and signposting (e.g. completing attendance

allowance). Unsurprisingly, this proudly independent couple sometimes needed convincing to claim what was rightfully theirs:

> ***'We had no idea that*** [we were] ***entitled to a carer's allowance and it was them that applied for it for us. I said, 'Why? We don't want a carer's allowance'. And they said 'But you are entitled to it'*** [Mr C interjects: 'I feel as though I'm cheating'] ***… we have to pay for a decorator now and use taxis…'***

While they were yet to utilise any of the dementia groups (and other resources offered) they none-the-less felt very supported by their DRS worker:

> ***'It felt as if we weren't on our own I could just pick up the phone, and she'd ring us, 'are you alright? Do you want anything? I'm coming up'. She looked up lots of things for us to help'***

Despite her glowing reports Mrs C still thinks the DRS is a very good idea *if you are lonely*, Mr C added poignantly 'I now rely on you an awful lot and I think if you passed away [this service] would be a good thing'. Indeed, as the interview developed it became increasingly apparent that Mrs C was the main beneficiary of DRS intervention as she now has to do many of the things that Mr C used to do, such as sorting out Road Tax, insurance and MOTs. She also needed help preparing to transfer ownership of their shop to their son, 'She knows what she's doing and anything you don't know she'll find out about'. DRS intervention has, according to Mrs C, 'filled in a lot of gaps we didn't know about'.

Catalyst for Change: Mr D

The impact of the DRS was occasionally quite dramatic, and none more so than for Mr D. Mr D has two daughters, one of whom lives locally. He has had numerous jobs over the years at home and abroad and owned a number of small businesses. Following diagnosis of Lewy Body Dementia Mr D became depressed and 'feeling almost like I wanted to end it'

> ***'I was a manager, marketing director of a big hotel, and suddenly I had no life at all…. It was a lonely time and I was very worried then suddenly I had someone to talk to'***

Mr D's support worker sat through the interview and he frequently turned to address her directly:

> ***'Literally from the time you first came, we got on well. You helped me so much it was just unbelievable. I felt I had to start something but I had this black cloud over me. I kept going to the GP. It was just the worst time in my life. You helped me so much'***

It was not simply emotional support Mr D received as he described in detail how he was helped with attendance allowance, joining a gym, rehousing and, most importantly, a system for remembering to take his tablets which means he no longer needs to worry about

forgetting them. As a result of the medication Mr D's mood has stabilised and because of the financial help he can afford to go to the pub with friends. Even his daughter commented: 'you've changed so much' he proudly recalled, adding, 'I feel totally capable of looking after myself independently'.

Perhaps most profoundly of all, as the interview drew to a close, Mr D started to talk of *losing* his dementia and linked this directly with the intervention of his DRS support worker.

> Mr D: ***Do you know the odd thing? I don't know when I actually found that I'd lost my dementia, for want of a better expression. Suddenly I was free. It was very odd***
>
> DRS Worker: *The medication has helped*
>
> Mr D: ***It's almost like a heavy weight…***
>
> Interviewer: *Maybe you've found a cure!*
>
> Mr D: [DRS Worker] ***is the cure!***

It is not, of course, being suggested that the DRS alone is responsible for this transformation but it has certainly been the catalyst for change in Mr D's life just as it has for many others. The support worker stood outside the chaos of Mr D's life and through her experience and expertise was able to help him make sense of events and piece it back together:

> ***'I had somebody who wasn't in the inner circle I could talk to. She could help me so I started to feel a lot better coz I could talk to someone who knows a lot more and could just ask questions which you don't want to ask your daughter about'***

Carer Crisis Intervention: Mr E

Mr E is a former scout leader and coalminer and lives at home with his wife. They used to enjoy outdoor activities and travelling home and abroad. Mr E has dementia and came into contact with his DRS support worker following a spell in respite, 'She provided the back-up that we needed, people we could get in touch with. She's just wonderful' he said. In particular, information and signposting was provided for dementia awareness, SALT, telecare and personal safety. Mr E is very independent and still does cleaning and washing up but he also becomes frustrated and angry which causes a strain on their marriage. One of the primary goals of the intervention was therefore to provide 'space' for the couple. A number of activities were tried, such as bowling, but these highlighted difficulties with numbers and names so arrangements were made for day care twice a week where he enjoys playing bingo and dominoes and paper reading: 'it makes me aware of some of the things that go on' he added.

Mrs E recalled a particular instance when she was not well and had to go into hospital and attend appointments. She was very concerned about how Mr E would manage without her but the DRS worker helped to arrange taxis to the day centre and daily checks at home for

him. DRS intervention has provided 'really good support' and helped the couple regain confidence to remain independent, 'It gave me confidence, a lot of confidence' Mrs E stated. Overall Mrs E says, DRS intervention has allowed her to have a more 'balanced life' and she has taken information to a support group she attends and has encouraged three members to get in touch.

A Marriage Saver: Mr F

Mr F is a former colliery engineer and handyman but was laid off due to COPD. 'Everything's gone in the last 12 months' Mr F lamented but he feels this is due more to his chest problems than anything else. Indeed, he doesn't believe the Alzheimer's Disease diagnosis, '[He] is not ready for dementia groups' Mrs F added. Despite this scepticism, 'Every time they've suggested something we have tried it' but, Mr F noted, 'some places have suited me but some haven't'. Unsurprisingly the ones that suited him were not dementia specific, like a local singing group. Their DRS worker additionally 'sorted out money' and 'took us out all over the place' but the real beneficiary has been Mrs F. She is now learning to paint, singing and attending music performances on which she commented:

> ***'It's marvellous. It's all free, connected with the council. I never knew that place existed, it's only down the road but I wouldn't have heard about it if it hadn't been for*** [DRS Worker]***…'***

This group led to another so they are now engaging with a number of community resources, which Mrs F described as a 'lifesaver'. She recalled a recent chance meeting with her DRS worker:

> ***'I saw*** [support worker] ***recently, and said 'When you took me to*** *[Group]****, it was a lifesaver'. It's amazing coz you join one group and it leads on to another. Because of*** [Group] ***and*** [support worker] ***we can go to the Tuesday afternoon and have a singsong'***

Mrs F is perhaps exaggerating the impact of the DRS and subsequent support. It may not have literally saved her life but perhaps it saved her marriage. Like many carers she is under a lot of strain and her relationship with Mr F has suffered as a result. This was highlighted when she conjectured what life would have been like *without* intervention.

> ***'I'd have packed my bags and gone by now. We've got two sons but I'm stuck. I haven't got sisters or anybody I can say 'yes, I'll go shopping with you'. So I would have been completely on my own. That's why I would have run off…I don't know where I would have been'***

Looking Ahead to Make the Most of Life: Mr G

Mr G has vascular dementia and a number of co-morbid conditions. He used to be a mechanic and showed dogs with his wife. They still enjoy gardening. Despite his complex needs Mr G's 'big worry' was for his wife (whose mother has advanced dementia) and

'putting everything in place' for her. Their past experience of dementia and the GPs forecast that he 'would end up in a home' left them feeling 'completely lost… We didn't know where to go. We didn't even know what we needed'.

Mr and Mrs G met their support worker 'by chance' at a Dementia Cafe but the consequences of this have been far reaching. They described many groups to which they had been taken (including carers associations for Mrs G) along with practical help with Council Tax, power of attorney and writing wills. All of this was however tinged with sadness as the couple could not help reflect on how different their experience of dementia has been compared to Mrs G's mother who 'had nothing' and how much better things *could* have been for her.

Mr and Mrs G keep Koi Carp and it was through encouragement from their support worker that they fulfilled their life-long dream of going to Japan. 'Dementia is not the end of the world' Mrs G concluded emphatically, though they once had every reason to believe it was. Mr G wrote to the Reablement Service thanking them for the intervention as follows:

> ***'From feeling down in the dumps and worrying about how my wife is going to cope with her mum who lives with us, who has dementia and needs fulltime caring, and me diagnosed with vascular dementia. My big worry was 'how is she going to cope with us?' Then by sheer luck we met*** [DRS Worker]***, who has turned our lives around. We have now just booked our dream holiday in Japan. I can't believe how much*** [DRS Worker] ***and the Reablement Team have helped putting us in the right direction and frame of mind'***

Intervention was not about doing things *for* Mr and Mrs G but simply guiding and supporting them. They were a resourceful couple who just needed reassurance that dementia is not, as they perhaps thought, 'the end of the world'. Indeed, as Mr and Mrs G demonstrate, people with dementia can still dream, plan and achieve.

> ***'At first we felt very alone and worried but with the help we gained confidence. We are now looking ahead to make the most of life'***

Service User Crisis Intervention: Mrs H

Mrs H was interviewed with her daughter. She is now in a residential home but had a DRS intervention when living at home. She did not need help with social support at the time of referral because, Ms H explained, 'she is very active in church'. She did however 'come close to trying things like a medication dispenser and sensors at home'. The greatest benefit of the DRS was at a time of ill health. Ms H was unable to take her mother to appointments so the support worker did this and 'kept notes of what the surgeons and people had said'. When hospitalisation was needed the support worker put Ms H in touch with someone at hospital 'who helps people with memory issues'. Few people know about this service, even at hospital, and it was a huge reassurance.

'It was more helpful for me than mum. I was juggling a lot of stuff and just wasn't coping. I don't have family. I have no safety net at all. [Turning to mum] ***It was just you and me, wasn't it? We've got family far away but not anyone who can get involved in things like hospital appointments. I could not have coped without them. End of. Full stop. They recognised straight away that I was spreading myself too thin'***

They would do anything: Mr I

Mr I has played sports all his life but had to stop 5 years ago due to a knee replacement. He still watches his old team occasionally but gets 'a bit teary'. He was diagnosed with early-onset dementia several years ago and still lives with his wife and one of his children. Mr I hates being on his own and 'Would be lost without my wife and kids'. He also hates being inactive so walks 6 miles a day. Mr I has been very active in dementia support and much of his conversation revolved around his disappointment at the closure of his (and other) peer support group. This is also where he was introduced to the DRS:

'Four ladies walked in from DRS. They were brilliant. I've never looked back since they got involved. They came round here and asked me what I want to do and stuck with me. It's been a delight. One of the best things I've ever done'

While diagnosed several years ago Mr I described a number of specific things the DRS was able to help with, particularly taking him to playing golf and introducing him to Men in Sheds. His support worker also helped set up his mobile phone, which was both important to Mr I and embarrassing given Mr I used to sell them for a living. As with most of the interview Mr I related everything to past support he had received and his disappointment at the closure of his peer support group, concluding 'I had some good times with [Agency] but nothing like the girls. They are so open and wanting to make sure I was ok. They would do anything I asked them to do'.

Real Problems: Mr J

Mr J has recently moved into the area from Staffordshire to be closer to his son who lives on a barge. He was in the army and had a number of other jobs before taking on a nomadic lifestyle for seven years, travelling the length and breadth of the country with his 2 dogs and caravan. Mr J has a number of additional health problems including spondylitis, COPD, diabetes, and hearing loss so the move from Staffordshire created a number of serious problems regarding medication, appointments and communication. His notes were not transferred, causing delays in medical support.

Mr J couldn't remember how the DRS became involved and has not taken up any of the suggestions made. He has no friends, he explained, and does not wish to socialise. He has not yet applied for a bus pass either but, he added, 'I've got the knowledge, I've not done it but will know what to do when I need it'.

Mr J did however recall a great deal of practical help with 'real problems'. He had, for example, been without hot water or heating since moving house and it was only because the support worker noticed how cold the room felt that any action was taken:

> ***'This place has weird heating. I couldn't understand but there was no heating and hot water. I wasn't getting anywhere. When*** [DRS Worker] ***come I was totally stuck. He got straight on to them and they sent somebody the same day… I can't praise it enough. It's just what a person like me needs coz I don't know who to ask'***

Mr J had already been diagnosed with dementia in Staffordshire and had been trying to get a referral to the local Memory Clinic for months

> ***'He's an* up and at 'em *kind of guy. Straight away he phoned them and I did all tests again. He's the right bloke for that job'***

The DRS has helped immensely in 'sorting out my real problems' noted, concluding:

> ***'If he wasn't about I may possibly still have no heating. I may possibly have never gone to the memory clinic. And I'm much more eased after he's been coz I've got an idea where to go. Now if I need something, I know who to ring up'***

Caring for Carers: Mr K

Mr K was a construction linesman and used to enjoy gardening, going to the pub and playing darts. He now likes watching TV and sports in particular. He is also very deaf and was therefore interviewed with his daughter present. 'He's always been forgetful', she explained, 'but we really started to notice when mum was unwell and she was saying 'oh, he's always forgetting things''.

Mr K likes his own company and is not interested in support groups, he's only been to one, his daughter explained, and didn't want to go again, but it was worth trying. The support worker none-the-less came regularly and 'would ask questions and then say, 'I'm going to so and so, would you like to come?' She'd take you anywhere. She was very good'. The support worker did however arrange an emergency alarm system, which has reassured father and daughter. She also helped with attendance allowance and appointments.

> ***'I don't know where I'd have been if she hadn't turned up… coz she's experienced she knew where to take me and what to say.*** [Daughter's] ***working long hours, I don't think you could have faulted her. She's got an attitude that puts you at ease straight away. She's brilliant she was'***

Ms K was indeed thankful for this support and for the regular communication in particular:

> ***'She was lovely. Nothing was too much for her. From my point of view, she'd always give me a call, let me know how they'd got on. She was very thorough in***

making sure I was up-to-date. She'd ring before-hand and then ring again, if not the same day, the day after'

Additional Feedback

In addition to the interviews and questionnaires a large amount of informal feedback was received either in writing (letters and emails) or by telephone. This was mostly routinely requested but often spontaneous. In all, almost 100 items of feedback were received between April and December 2015. While generic compliments for 'an excellent service' may be expected, and were indeed common, the majority of feedback was in fact very specific and corroborated evidence already reported in this evaluation highlighting, for example, the personal qualities of DRS workers (on no less than 40 occasions) particularly with respect to their professionalism, effectiveness and friendliness. Although clearly inter-connected, other frequently repeated impacts and outcomes (again reflecting and corroborating survey data) included:

- living with more purpose and direction e.g. hope for the future (13 occasions)
- improved sense of wellbeing e.g. mood (12 occasions)
- feeling less isolated (8 occasions)
- greater confidence (6 occasions)
- understanding dementia better (5 occasions)

See Appendix 2 for examples of compliments received by the DRS teams.

Professional Interviews

In order to gauge how effectively the DRS fits in with wider service provision 13 interviews were undertaken with a range of dementia specialists who have worked directly with the service. These included 2 consultant psychiatrists, 4 senior managers, and a range of frontline practitioners. The interviews were open ended (exploring what is working well and what is not working well) so the themes presented below emerged naturalistically. That said, it is unsurprising that responses reflected relationships with DRS so that those who referred service users to the service focussed on aspects of this while those who worked in the community delivering support (Dementia Advisors) focussed on this. The former were unanimous in their praise for the DRS while the latter were more mixed.

Ease of Referral

The first and perhaps most obvious impact of the DRS has been on the ease with which referrals can now be made to specialist dementia support workers. A particular and often repeated benefit included being able to make referrals over the phone, along with attendance at team meetings and documenting activities on Care Notes. This provides an invaluable link between service users and practitioners who may otherwise only see each other once or twice a year, as one interviewee noted, 'It is really helpful coz I can see what they've done and where they're up to'.

According to interviewees, services were previously fragmented and practitioners were using lots of different agencies. Now however the DRS 'seems to pull it all together - which saves us time'. One interviewee recalled how the team struggled to know who to refer to but '…now we just don't think twice we just refer to the DRS and we know that all the areas we are worried about will be covered by them', adding:

> ***'It's so much easier to refer to the DRS. You pick up the phone, speak to someone, they are happy to take a referral off us on the telephone or we can email them. They have access to our computer data about the patient so they can go on the patient's confidential notes and see exactly where they are'***
>
> *Practitioner*

> ***'They are so helpful. Whenever I phone up they are really accommodating. It's made a big difference to me. I feel I've got something much more to offer people when they come for their appointments'***
>
> *Practitioner*

Joined-up Working

The key to this success appears to be the positive relationships that have been forged with Memory Clinics and Older People's Mental Health Services, despite long-standing cultural differences between health and social care.

> ***'Obviously we are an integrated team anyway with Cheshire East Council but there's still a bit of a 'them and us' mentality, but the Reablement Service feels part of our team'***
>
> *Manager*

Attendance at multi-disciplinary meetings was highlighted as particularly useful by several participants:

> ***'Every Monday we have our multi-disciplinary meetings and a member of the DRS comes, so we have direct access. The referral system is very quick. They seem to have the appropriate number of experienced staff to pick the situations up and we are getting good feedback from the service users about the contact they are having with them. Whereas before if we had to refer someone for assistive technology, where different services were involved, we would have to do that whereas now they are able to see them more than we are'***
>
> *Manager*

This partnership has developed not just by working collaboratively with dementia specialists but, as illustrated above, also demonstrates the skills and outcomes necessary for

confidence to grow over time. Because of this they can be trusted to practice what other practitioners only preach and support service users to become active citizens

> ***'If following assessment someone is having difficulties accessing social activities, then I'll refer them and it's been really useful. As we've gone along I've found they can do a whole range of things, which is really helpful for me as a practitioner. My role is assessment and I pass on the intervention'***
>
> *Practitioner*

The Missing Link

The DRS does not just take referrals but makes them too, providing an invaluable link between specialist support and the community.

> ***'I'm very focussed on people leading active participatory lives. As someone who only sees users once or twice a year it's very hard to provide that kind of support. They've given me a link'***
>
> *Practitioner*

Good use of the voluntary sector was evident throughout this evaluation and while not involved in interviews a number of participants talked about how they felt the profile of dementia has been raised in the community by utilising generic social activities rather than dementia specific support. This is helping to raise awareness of dementia in the community and provides service users who are 'not ready' for dementia specific activities with necessary support. This may be an explicit goal but could just as easily be an unintended social benefit of an unrelated activity, such as supporting someone to attend a falls prevention group, as the following interviewee demonstrates:

> ***'One lady was identified as a significant falls risk and I'd identified a falls prevention group and they were able to take her to that. She hadn't been going out before that so she was getting the social benefits along with falls prevention. She was pleased with that and her daughter was reassured too'***
>
> *Practitioner*

Sustainability is a key issue for service users and while the majority were satisfied that they would continue the plan (with the reassurance that they could contact the service in future if needed) others were undeniably anxious. This was also reflected in professional interviewees who have 'picked up on sense of abandonment' and expressed concern about raising expectations that cannot be met with the limited resources available. Existing community services simply cannot keep up with demand without compromising quality or simply not being able to deliver:

'We have one worker and a small group of volunteers so if a person with dementia wants to attend and has certain needs we need to be able to recruit more volunteers coz otherwise they are not going to have a positive experience'

'It's a fantastic thing but concerned that users are disoriented and disappointed coz if they are taken dancing and then it stops. We'd love to be able to do that but we just don't have the funding. If that kind of service is going to be delivered it needs to be properly thought out'

'I have had some service users that have been able to attend groups with Reablement workers but when the case is closed they are no longer able to go'

Teething Problems

While overwhelming in their positive feedback, interviewees also highlighted some teething problems, particularly with respect to working with existing dementia services.

'It has caused delays in us getting a referral where we used to get them at that point of diagnosis, we still get some that way but there has been a noticeable reduction. So that we tend to get them after that 12 week period. This has caused some gaps and delays and a little bit of confusion in terms of duplicating a little bit'

Established clinical pathways predate DRS and other agencies have traditionally acted as the first point of contact following diagnosis providing a range of services. A number of interviewees identified apparent changes in the DRS remit and referral criteria (i.e. from a 6 week intervention up to 12; and from a focus on 'newly diagnosed' people to 'anyone' *sic*). However, this appears to have been agreed with referrers - while there is capacity at least:

'We've been given referral guidelines and they target early diagnosis and we said 'well, what about the people we've been seeing for years', and they said 'yes'. I presume that as their waiting list grows, they're going to have to say no to that. It would be nice if they could see everyone'

Some interviewees reported a decrease in referrals to contracted services while others did not, and some saw this as positive while others did not as referrers regarded existing services as inadequate, though improving:

'X is nowhere near as good as the DRS. I lost faith in them with their XXXX service which has a one year waiting list. And when you phone up they'll say 'you have to fill out a written application form'. They put up a lot of obstacles. You'd often ring up and you'd get an answering machine…'

'X have picked up a bit since DRS got involved. They offer more carers groups and the XXXX service seems to have perked up a bit. But I've stopped referring to them, I just ask the DRS to do it now. Just because it's easier'

Not everyone reported changing referral patterns, 'We still use other agencies, we're not bypassing anyone'. 'I'll be totally honest', remarked one Dementia Advisor, 'When it first came out I wondered if we would be getting as many referrals. It's not that at all. I can't praise them highly enough!'

It is important to note that this difference of opinion seemed to depend on which of the existing service providers interviewees were linked to. This split seemed to underpin reports of (potential and actual) duplication with one reporting 'No conflict. There is plenty of work to go round' while another recalled 'having to go over the advice they've been given to fill in the gaps, give a bit more information and then start the process again'. 'People often have the best intentions' added another 'but we end up picking up the pieces'. Again this is in stark contrast with another who stated

> ***'I've had a lot of feedback. If they've gone out before me, I usually ask about the service and I've never heard anything negative: 'So and so is lovely' or 'full of life'. I've only ever heard good feedback. It is something I usually ask'***

Another key issue raised was the (initial) confusion created by the DRS. One key referrer admitted 'it's taken a while to get my head around it' and was concerned that 'the person can be referred to too many people'. Anecdotally one interviewee indeed recalled an instance of three agencies being simultaneously engaged while another speculated that service users were confused by the range of interventions:

> ***'We are dealing with people who are a little bit confused and there are other organisations involved such as*** [Agency] ***and they'll be like 'how do you differ from the person who contacted me last week? You're offering to come out and see me but they're offering to come and see me. What do you do that they don't do?''***

The more critical issue is, of course, the impact on service users. There was little indication from interviews that service users are affected but one indicated it is 'a bit confusing':

> ***'It's a bit confusing. There's the Dementia Society*** [sic] ***and Alzheimer's. Why isn't there just one group? It seems as though sometimes they are fighting… And Age UK. They are all fighting for funding'***

Perhaps even more concerning, when questioned about how he knew about this, the service user responded that it was from 'chit-chat' at the groups he attended, suggesting a collective concern not only about the co-ordination of services but also their future.

LEARNING FROM THE DRS TEAMS

The hard work, compassion and enthusiasm of DRS workers was evident throughout this evaluation and, in the opinion of the authors, underpins the success of the pilot. As already noted, their personal qualities were the overwhelming focus of feedback and interviews and

this should not be overlooked. At the first meeting of the DRS workers the aspirations and desired outcomes to which the team would be accountable were established. The team wanted to make a difference at both a community (macro) and individual (micro) level whilst also establishing a strong and credible evidence base:

Macro	Evidence	Micro
Build a good reputation/service	Positive feedback from clients/carers	Support people to be prepared for the future so the person isn't lost/left alone
Build strong partnerships with other agencies	Improved Quality of Life	Empower people/give them control
Raising profile and understanding of dementia	Confirm that there is a gap in current services	Provide information and choice
Better educated: community, person, carers		

Figure 23

These aspirations have almost a perfect match with Cheshire East Council's Vision Statement for the service and go some way to explain how the organisational rhetoric is becoming reality in people's lives. Desired outcomes were discussed at length by DRS workers and divided into the short, medium and long term goals for service users:

Short	Medium	Long
Empowerment	Reduced stress and reliance on family carers	Remain independent
Increased independence/ confidence	Trust in services	Staying at home
Increased social inclusion	Supporting carers	Reduced stigma
Building a network of support by accessing groups	Bigger network of support	

Figure 24

While outcomes have been met in the short-term, the future is of course much less certain. DRS users and carers certainly feel that they will be able to look after themselves and retain their independence for longer but only longitudinal data will confirm if this is the case. It is also too soon to know whether the DRS has delayed or reduced the need for social care intervention or emergency services etc. There were one or two instances of this during interviews but, more importantly, the scaffolding necessary to avert crisis and prevent avoidable admissions is now in place for many. Indeed, one of the strongest messages from the data is the readiness of participants to face the future armed with new information, access to support and, most importantly, confidence.

The sustainability of this renewed hope is not, however, simply dependent upon the resilience of service users and their families or indeed the quality of the DRS itself but also on the readiness of communities to welcome people with dementia and the availability of resources. This was again a key and often repeated message from the Action Learning sets with DRS workers who from the very outset discussed barriers to success and provided numerous accounts of support groups and activities quickly reaching capacity and people not being able to access transport services as needed. As already noted, many dementia specialist services are also running at full capacity and often have long waiting lists while Dementia Advisors interviewed for this evaluation similarly reported being unable to recruit volunteers to meet increased demand for groups.

DRS workers spent considerable time during Action Learning sessions reflecting on many other barriers to progress and what could be done to address them. These are summarised below:

Gaps Identified				
	Provider	**Service**	**Evidence for Gap**	**What's Needed**
1.		Other professionals involved with service user eg GP	DRS service users are not up to date with hearing and eye tests. Missed by other services, eg GP. DRS needs to focus on Dementia.	Other professionals to check when last hearing and eye tests were undertaken
2.	D&G	D&G Little Bus	Service available daily in Crewe but only available two days per week in other towns, e.g. Sandbach. Available days don't necessarily coincide with groups/activities.	More buses
3.	Dennis Round – sheltered housing	D&G Little Bus	Restricted to certain journeys because some routes fully booked.	More buses to run on more days, with more flexibility
4.	Community Cars	Taxi service run by volunteers	Restricted to 2 return journeys/week. If volunteers not available then service does not operate	Opportunity to make block bookings
5.	Alzheimer's Society and	Befriending scheme	Long waiting lists – full to capacity.	

	Age UK		Operates out of	
6.	St Lukes Hospice	Befriending scheme	Lack of volunteers, and only operates in Crewe and Nantwich	More volunteers
7.	Alsager Community Network	Befriending scheme	Run by volunteers – may reach capacity, limited funding	
8.	Haslington Network	Befriending scheme	Run by volunteers – may reach capacity, limited funding	
9.	Wishing Well	Lunch Clubs	At the Jubilee Luncheon club – at capacity on Mondays and reaching capacity on a Friday	
10.	Dennis Round	Lunch Club	At capacity on a Monday	More space and volunteers needed.
11.	CEC	AT	Long wait time for referral.	Need another AT post to cover the South, so that Dave is not the only AT.
12.	Age UK East Cheshire	No Dementia Well-being Coordinator	No-one available to complete benefit forms	A Dementia Well-being Coordinator in position in the East.
13.		Day care	Handforth – 30 week wait Poynton – 18 week wait Mobberley – works on a 6 week rota. Data provided by Provider on 2.10.15	More day care places
14.	Alzheimer's Society	Singing for the Brain – Macclesfield	Verbal	More sessions available
15.	Cheshire East Council	Lack of Community Agents	Service users DRS Support	More?
16.	D&G	D&G Little Buses in Disley and Goostrey (and generally transport in rural areas)	Feedback from Reference Group, and the Booking system	More rural transport

Figure 25

SUMMARY OF EVIDENCE

In brief, the DRS has been highly effective in meeting the DRS outcomes - within the parameters of this evaluation - and the sources of evidence for this are summarised in Appendix 3.

COST BENEFITS OF THE SERVICE

In addition to the qualitative and quantitative evidence presented in this evaluation report, it is necessary to also consider the cost effectiveness of the service, and establish whether the service can indeed delay/reduce the need for social care. To that end, data has been provided by the Cheshire East Business Intelligence Team which compares the chargeable social care costs for clients with dementia who have received the Dementia Reablement Service, to those clients with dementia who have not.

The following table shows two groups of people who have all been diagnosed with dementia in either 2014 or 2015.

The ***Control Group*** includes people who have not received the Dementia Reablement service and the 6 week, 12 week and 6 month dates are calculated using their diagnosis date.

The ***Dementia Reablement Group*** includes people who have received the Dementia Reablement service, and the 6 week, 12 week and 6 month dates are calculated based on the date that they finished their Dementia Reablement service.

		Number with Chargeable Social Care provision			Percentage with Chargeable Social Care provision			Average Weekly Cost of Social Care provision for those receiving services		
	Number in Group	After 6 Weeks	After 12 Weeks	After 6 Months	After 6 Weeks	After 12 Weeks	After 6 Months	After 6 Weeks	After 12 Weeks	After 6 Months
Control Group	583	163	176	183	28.0%	30.2%	31.4%	£253.86	£250.30	£275.02
Dementia Reablement Group	210	63	63	63	30.0%	30.0%	30.0%	£109.24	£126.89	£185.44

Figure 26

The data shows that although the *percentage* of people in receipt of chargeable social care services after 6 weeks, 12 weeks and 6 months is similar for both groups, the *cost* of the services they are receiving is significantly lower for those people who have received the Dementia Reablement Service. Based on this sample of people, the cost of the chargeable

social care provision for people who have received the DRS is only 43% of the cost of services for those people who have not received the DRS at the 6 week point, and 51% of the cost at the 12 week point and 67% at the 6 month point.

Cost of Providing the DRS

Based on an estimated average of around 12 hours spent working with each client(estimated from the Contact data from the DRS teams, and validated by DRS Managers), and the average hourly rate of employing a Senior support worker (£20.79), the average cost of a customer receiving the Dementia Reablement Service is approx. £250.

Net Cost Avoidance

Assuming that the 6 week cost applies between 6 and 12 weeks, the 12 week cost applies between 12 weeks and 6 months and the 6 month cost applies between 6 and 12 months we can make the following estimates:

Average cost of a Control Group client's chargeable social care that they receive between 6 weeks & 12 months = £11,127.24

Average cost of a DRS client's chargeable social care that they receive between 6 weeks & 12 months = £6,878.68 (£6,628.68 plus cost of DRS service £250).

Therefore the average potential social care cost avoidance per client in the first 12 months can be calculated as £4,248.56. This represents a significant reduction in the level of social care provision required.

The data shows that the % of DRS clients requiring chargeable social care provision after 6 months following the end of the DRS is 30% (63/210). If this percentage is applied to the number of DRS client referrals in the past 12 months (July 15 - June 16) - 30% of 634 clients, this results in 190 clients.

If the average potential cost avoidance is applied to these 190 clients, this generates an **annual potential cost avoidance of £807,226**, a significant sum of money. It also demonstrates the delayed need for more expensive social care provision.

CONCLUSION

The evidence of this evaluation suggests an objective stabilising effect on general sense of wellbeing and overall quality of life. This is no small achievement against a backdrop of expectations to decline and retreat into oblivion. However, and perhaps more importantly than generic QoL measures, there is *overwhelming* evidence that service users and carers feel more confident about remaining independent for longer at home while also feeling informed about future options. Indeed, for each of the eight intervention specific measures (for both service users and carers) no less than 95% of respondents agreed or strongly agreed that the service had made a positive difference in their lives. Professionals too were

unanimous in their praise for the service highlighting ease of referral, integrated working and linking otherwise disparate services together. Perhaps most importantly in-depth qualitative interviews demonstrated a wide range of person centred practice that is transforming lives. This was more often than not a gradual process of incremental improvement in relation to specific issues but on a number of occasions change was radical and total, as one particular service user's feedback makes clear:

> '***X has made a huge difference in my life. I feel she has brought me back into the world. I now feel that my condition will not define who I am. I am Valerie[1] who happens to have dementia. Everything is said from the head'***

Not only has the DRS enabled people with dementia to feel more confident about remaining independent for longer at home, it has also been demonstrated that the DRS can provide a significant cost avoidance for adult social care costs. The economic and personal costs of dementia combined with evidence of the patchy service provision in Cheshire East prior to the introduction of the DRS, provide a powerful argument for the need for the DRS to continue.

Ironically, by successfully enabling and empowering service users the DRS is in danger of becoming a victim of its own success. Unless a commensurate investment in specialist and non-specialist community services and infrastructure is forthcoming, disappointment seems inevitable particularly for those in most need. Until then, it is imperative that service users are not only cognizant of the short-term nature of the intervention but also that DRS workers do not give unrealistic expectations or instigate long-term plans that cannot be sustained. This has been achieved within the limits of available resources but communication with service users and professionals in relation to what is possible in a climate of austerity and cuts could be clearer.

The DRS has without doubt fully satisfied their remit to provide timely, flexible and brief person-centred interventions but this has not always been consistently delivered or in line with expectations of other professionals who appeared, for example, expected existing clinical pathways to continue as before and to remain the first point of contact following diagnosis. There was also the widely held belief that the DRS was for newly diagnosed people only when it is in fact for anyone in the early stages of dementia (which for those with mild symptoms / slow progression may be several years post diagnosis). As already noted, this appears to have been agreed with referrers (while capacity exists) but DRS literature is unclear and the information has not been communicated with referrers / other community providers effectively enough. This, along with the (potential) confusion about who should do what and when, will no doubt become clearer over time but until then a clear Clinical Pathway needs to be communicated to all concerned and followed consistently.

[1] Pseudonym

RECOMMENDATIONS

This evaluation demonstrates and asserts with confidence that the DRS pilot has provided an excellent and effective service and has fully met its aims and objectives. As might be expected there have, however, been one or two teething problems and barriers to success that need to be addressed, so the following recommendations have been made:

- **Clinical Pathway**: It is recommended that the established Clinical Pathway should be revised in order to properly reflect entrance to and exit from the DRS (and partner agencies and resources) and this should be clearly communicated to service users, referrers and community services alike.
- **Consistency:** Greater consistency is needed between North and South teams in the referrals that are taken and timing of first contact, initial visit and closure. It is recommended that positive steps are taken to monitor, manage and maintain a consistent approach between teams across the region.
- **Expectation Management**: Service users and professionals alike should be more aware of the possibilities and limits of DRS intervention. It is recommended that existing information and literature should be re-examined and revised so that future guidance properly reflects evolving aims and objectives.
- **Sustainability**: DRS workers should only initiate that which is achievable within 12 weeks and / or independently sustainable after completion of the intervention.
- **Collaboration:** Integration with health partners is evident and should continue to be a priority (e.g. embedding the DRS within referral processes, sharing information and attending team meetings to provide regular updates). Integration with community partners has been more mixed and providers need to complement each other rather than compete for limited resources.
- **Whole Systems Approach:** The DRS is in danger of becoming a victim of its own success. Workers have made creative use of limited resources but bottlenecks in the system, transport and infrastructure, and attitudes still need to be challenged and changed by, for example, putting pressure on strategic decision makers to take responsibility for our most vulnerable citizens and understand that the health and wellbeing of people living with dementia is everybody's concern.
- **Recommissioning**: The DRS should continue to be commissioned. Ideally this should be done jointly with health partners to ensure a seamless service that compliments what is already happening (or not happening) particularly in the light of on-going cuts both within and out-with specialist services. Cheshire East Council should therefore consider funding the DRS (along with existing community partners) jointly with the CCG to ensure a fully accountable and integrated service for all.
- **Further Evidence:** The DRS should continue to be evaluated in order to establish longitudinal data regarding sustainability, bottlenecks and barriers in the system, impact on the wider community and services, and cost-benefit analysis. This should

include consideration of the social return on investment such as delaying the need for care, avoiding unnecessary admissions and reducing GP appointments.

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APPENDICES

Appendix 1 – Case Studies

Case study 1: Mrs L

Background

Mrs L lives with her husband K , they have been married for 57 years and lived in Knutsford most of their lives. They have two very supportive sons who live within a 15 mile radius of them. Mrs L is 80 years old and has a diagnosis of Dementia (Alzheimers Disease). She has arthritis in her knees and walks with a pronounced limp, she has just been advised to give up driving. She is type 2 diabetic. They have no formal support but have a gardener .

On first meeting Mrs L, her husband K and both sons were present, they obviously have a strong family bond. Both sons were concerned that their father was not getting a break from his caring role and were interested in exploring social activities that both Mr & Mrs L could do together and asked about a medication carousel to prompt Mrs L to take her tablets. They had an Attendance Allowance form but this had not completed.

DRS Intervention

Firstly a referral was made for assistance with completion of the Attendance Allowance form. This was given via the Community Agents, Mrs L has now been awarded the higher rate of AA and they, with support of their sons, are looking into getting help with domestic chores. The community agent is to assist them to apply for a reduction in council tax which they are now entitled to.

A referral was put on for a medication carousel, but in the end it was declined as it was felt that Mrs L can be prompted to take her medication by her husband and it's Mrs L actually deciding to take it that is the issue.

Assistance was given to them to apply for their bus passes, they had not needed them previously as they both drove. With the bus pass they were able to register for the D&G flexible transport. Support was given to register for this and information printed out with instructions on how to use it.

Case Study 2: Mr M

Background

Referral from Memory clinic for Mr M. On first visit Mr M said that he was perfectly happy and needed no input from ourselves, His daughter was present and voiced her concerns about Mr M living alone and neither her or her sister lived locally so were concerned that if Mr M was to have a fall or become unwell there was no way of them knowing. I sensitively discussed with Mr M about having some Telecare installed, and discussed the different

options. Mr M agreed that it was a good idea to have falls pendants in place before a crisis happened. I referred through to SMART team who went and did an assessment and the Telecare is now in place. Mr M also admitted he was lonely, but didn't want to attend any luncheon clubs at present as he likes to visit his wife daily, who is in a nursing home. Mr M also said that he wasn't very good at preparing meals for himself, although he wasn't interested in a hot meal delivery.

DRS Intervention

I discussed maybe having an agency coming in through the week and gave them a directory of different agencies that offer home assistance. Mr M opted for Home Instead, so I spoke to Home Instead to refer Mr M and they are now doing 4 hourly calls per week.

Mr M also identified he has issues with remembering to take his medication correctly, so I discussed a Medication carousel with him, and referred through to Plus Dane who fitted a Medication carousel in Mr M home.

I also sent for an Attendance Allowance form, and on delivery of this, I rang and booked an appointment with the Community Agents to come and assist with the form filling which is now complete.

In reflection, on first visit, Mr M stated that he required no input from Dementia Reablement Service, but with a gentle approach, different services were put in place to ensure Mr M remains safe in his own home, but he doesn't feel he has lost any independence or control over his life, but has given his family peace of mind that he is safe, taking his medication and is eating a balanced diet.

Case Study 3: Mrs N

Background

Mrs N is an 87 year old lady with a diagnosis of dementia who was referred to us by the memory clinic. She lives with J, her husband and carer, in Poynton. Mrs N has not left the house since having a bad fall last year and lacks the confidence to even go out into the garden as she says she is too afraid of falling.

DRS Intervention

When I first started visiting them, her husband could only go out and leave her for short periods, e.g. to go to the local shops, or for a bit longer if a family member came to sit with her. Mrs N was friendly and talkative and enjoyed chatting with me on my visits, telling me about her family and her life when she was younger. It became apparent over subsequent visits that it was becoming harder for her husband when he was with her at home (e.g. not letting him watch his programmes on TV and becoming frustrated if he reminded her to put her feet up) and he was in need of a break from his caring role. They had been receiving

some support from The Red Cross with their short-term sitting service but this was due to come to an end so I suggested setting up a regular arrangement for an agency to provide a sitter. Initially J was reluctant, saying they could manage without, but I explained that an agency could send a regular carer whom Mrs N would get to know (just as she had got to know the one from the Red Cross) and that he would be able have a few hours to himself each week. I explained to Mrs N that the carer would be able to chat with her about her family and things she had done when she was younger, just as she had with me, and Mrs N said she would like that. I offered to give J information about agencies but he said that a friend had used a local one and recommended it to him. He didn't want to phone the agency so, with J's permission, I visited them, explained the situation and arranged for them to contact J to make an appointment for an initial assessment. I explained the process to J and Mrs N and a regular sitting service was set up for 3 hours every Friday evening so that J could meet up with his son and friends in the pub, and Mrs N had some female company and someone to chat to while he was out. I also explained to J that in the future the service could be extended to include more sessions so that J could go out and leave Mrs N without worrying, have a break from his role as carer, and Mrs N would have some quality time with a carer she knows and likes.

Case Study 4: Mr O

Background

Mr O is an 87 year old man with dementia who lives with his wife Mrs O and son A in Poynton. His wife has mobility and health issues and doesn't leave the house. At the initial visit his son expressed concern that his parents spend all their time together, other than when Mrs O goes to the local shops to buy her cigarettes, sometimes several times a day. The son felt when at home they argue a lot, Mrs O tells Mr O what to do, and Mr O spends time outside to have a break from his wife. The son thought it would be beneficial to both of them if Mr O had some time to himself, away from his wife and the home, so that they could have a break from each other.

DRS Intervention

Mr O has previously enjoyed doing DIY and gardening so I contacted Poynton Men in Sheds, a group run by Poynton Town Council at the Community Centre on Park Lane. I explained to Mr O what kind of things they do there and asked Mr O if he would like to try it and he said he would. I supported him to attend the following week and stayed to introduce him. There were a couple of other men there that he recognised from the village and they made him a cup of tea. I let him have some time there to mix with the others and then supported him home later but when I returned he had decided to walk home. He said he had enjoyed it and had been helping to paint the railings at the front of the building. He said he would like to go again so we did the same the following two weeks. Mr O has attended several more times and, now that he knows it's there, he can go each week if he wants. His son reminds him

that ‘it’s Men in Sheds today’ and Mr O walks there and back. Mrs O asks him what he’s been doing there and he talks about it a lot. Men in Sheds gives Mr O somewhere to go to mix with other men, do activities he enjoys and have a break from being at home with his wife. Mrs O has a chance to spend time alone to watch the TV or read and they get on better when they are together. I have also told Mr O that there is a drop-in group at the civic centre on Friday afternoons if he wanted to go to that as well. Some of the men who go to Men in Sheds attend so he would know some of the people there.

Appendix 2 – Compliments

DRS Compliments.pdf

Appendix 3 – Sources of Evidence

Outcome	Evidence
PLWD feel that they will be able to look after themselves and retain their independence for longer	• Qu No. 2 (11, 12, 13) • Narrative Summary • Information and Support Plan
Families and carers of PLWD will be supported and reassured that their family member can safely live independently	• Qu No. 14 (15) • Carer Evaluation Final Statement • Interviews • Narrative Summary
PLWD will be empowered and confident to live independently	• Qu No. 2 (11, 12, 13) • Interviews • Feedback • Case Studies
Social isolation will be reduced for PLWD, and their carers	• Qu No. 3, 4, 8 (14, 15) • Professional Interviews • Feedback • Information and Support Plan
PLWD can choose and have easy access to the type of support they need, when they need it	• Qu No. 5, 13 (9, 10, 16) • Service User Evaluation Final Statement

Delaying the need for formal social care interventions e.g. residential/ nursing care and preventing the need for crisis interventions and support e.g. Social Care Emergency Duty, GP Emergency Out of Hours and Non Elective Hospital Admissions;	• Qu No. 12, 15 • Interviews
PLWD and their carers feel more informed about their options for the future;	• Qu No. 13, 16 • Service User Evaluation Final Statement • Interviews • Carer Evaluation Final Statement
PLWD and their carers feel they have a good quality of life.	• Qu No. 1, 6, 7 • Interviews • Feedback