An Evaluation Report on the Dementia Support Worker Initiative of the 5 Steps to Living Well with Dementia in South Tipperary Project

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We are extremely grateful to the people who took part in this research for the time, honesty and openness they shared with the researchers about their experiences. Their insights will influence the development of community-based dementia services available to others in Ireland in the future.

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FOREWORD

In 2012, four sites around Ireland received funding to develop a range of innovative community responses which would enable people with dementia to remain living in their homes for as long as possible, having full and participating lives. This initiative was part of a programme of work funded by the Health Service Executive and the Atlantic Philanthropies to develop, expand and improve community-based dementia services in Ireland. Alongside the innovative work being carried out in four sites, a supporting programme of research and evaluation was commissioned to evaluate the new developments and to collect preliminary evidence on which to develop future dementia services.

This report describes an evaluation of an innovative respite initiative in one of the sites; South Tipperary. The focus of the initiative was to provide individualised supports for people with dementia and their family carers using dementia support workers. This study was carried out in the early stages of the development of this respite service, involving 8 people with dementia and 12 family carers. Although it is a small scale exploratory study, the use of mixed methods, capturing both quantitative and rich qualitative data, provides new insights into the experiences of living with dementia, the caregiving role and the impact of this initiative on both.

There was a high level of satisfaction with the service expressed by both the person with dementia and the family carers. In particular, the flexibility and responsiveness of the service were highly valued and the individualised tailored activities for each individual conveyed further benefit. In addition, having the same dementia support workers consistently and their training, skills and professionalism were noted as being very important factors in contributing to the positive evaluation of the initiative.
It is worth noting that the report captures this initiative at a very early point in time and that, in response to feedback from the individuals and families using the service, as well as input from other stakeholders and the findings of this evaluation, the service has been significantly redesigned to be more responsive to the diverse and complex range of individual needs that present. An evaluation of this redesigned service is planned for 2015.

I would like to thank the participants for sharing their experiences and insights with the research team. Their contribution will feed directly into the future development of community-based dementia services. I also wish to acknowledge the excellent work of the researchers; Prof. Suzanne Cahill, Dr. Maria Pierce and Dr. Andrea Bobersky. We are grateful for the support of the Atlantic Philanthropies in funding the research work which has resulted in this report. We hope that these findings will inform and contribute to the ongoing work in Ireland now required to further support people with dementia and their family carers who in Ireland provide the main bulk of dementia care.

Dr. Fiona Keogh, Director of Research and Evidence, Genio

TABLE OF CONTENTS

1. INTRODUCTION 4
2. PURPOSE OF THE DSWI 6
3. METHODOLOGY 9
    3.1 In-Depth Interviews 10
    3.2 Quality of Life Scale (QOL-AD) and Caregiver Burden Scale (ZBI) 11
    3.3 Interview Schedule 12
    3.4 Profile of Participants 12
4. RESULTS 13
    4.1 The Organization of the DSWI 13
    4.2 Accessing the DSWI 14
    4.3 Assessment and Care Pathways 15
    4.4 Flexibility 17
    4.5 Effectiveness of Respite Services in Meeting the Needs of Persons with dementia 18
        4.5.1 Choice 19
        4.5.2 Linking Activities to Life Stories 19
        4.5.3 Developing New Skills 20
        4.5.4 Person-Centered Interaction 20
        4.5.5 Supporting Autonomy 21
        4.5.6 Effectiveness in Meeting the Needs of Family Members 21
        4.5.7 Validating Concerns 22
    4.6 Participants' Perceptions of DSW Staff 23
        4.6.1 Communication Skills and Professionalism 23
        4.6.2 Consistency 24
    4.7 Care Needs and Formal Support Services 25
    4.8 Other Formal and Informal Respite Support 26
    4.9 The DSWI vis-à-vis Traditional Models of Respite Services 29
    4.10 The DSWI and Need for Hospital Care 29
    4.11 The DSWI and Need for Long-Stay Residential Care 30
    4.12 Caregiver Strain 31
    4.13 Correlates of Burden and Home Care Continuation 34
        4.13.1 Anger 34
        4.13.2 Embarrassment 34
        4.13.3 Home Care Sustainability 34
    4.14 Quality of Life 36
        4.14.1 Insight 38
        4.14.2 Enjoying a Good Quality of Life Despite Dementia 39
        4.14.3 Contribution of DSWI to Person with Dementia's Quality of Life 39
        4.14.4 Improvements Noted in Family Caregivers' Quality of Life 40
    4.15 Satisfaction with the DSWI Programme 41
    4.16 Sources of Concern 43
        4.16.1 Stopping a Valuable Service 43
        4.16.2 Uncertainties and Fear of the Future 44
        4.16.3 Other Concerns 44
5. CONCLUSIONS 45
REFERENCES 49

1. INTRODUCTION

In 2012, The Atlantic Philanthropies and the Health Services Executive (HSE) entered into an agreement with Genio to fund and undertake an initiative, demonstrating new models of community supports for people with dementia and their family caregivers across different demonstration sites.

Genio is a not-for-profit organization that works with the public, private and non-for-profit sector to stimulate and support social innovation, which will have a lasting impact in Ireland. To support social innovation, Genio brings together people from Government, health and social service sectors, advocates, social policy experts, NGOs and the world of business. Genio's focus is on those for whom opportunities to participate fully in society and live as full and valued members of society are hindered. Genio's programme of work has focused on people with disability and mental health problems. Through funding from The Atlantic Philanthropies and the HSE, Genio is now bringing the experience gained in the disability and mental health sector to people living with dementia.

In 2012, the *5 Steps to Living with Dementia in South Tipperary project* (from here on in known as the 5 Steps Project) was one of four sites selected for funding through the Genio Dementia Programme. As part of its programme, the 5 Steps Project established the Dementia Support Worker Initiative (DSWI) to demonstrate how new models of respite could support people with dementia to live meaningful lives whilst at the same time offering support and time out for family members caring for them.

Respite is a key support service for people with dementia and for family caregivers and, although there is limited evidence of the effectiveness of different models, caregivers have consistently expressed high levels of satisfaction with respite support (Bamford, 2013). Respite can be defined as any formal service designed to provide a break from the usual routine for people with dementia and their informal caregivers (Bamford, 2013). The three main types of respite provided for people with dementia in Ireland (Cahill et al, 2012) are: (i) day care, (ii) in-home respite and (iii) residential respite. The latter is where the person with dementia spends time away from home, usually in a long-stay care environment.

Traditionally, respite has been understood as a service that 'physically or socially separates one party out for the benefit of the other' (Armstrong & Shevellar, 2006). The primary concern of respite has been on giving family caregivers a break from the caring role. A feature of some of the newer models of respite is that they are also concerned with how the time of the direct recipient of the service, i.e. the person with dementia, is spent, when away from the caregiver. This is in keeping with the broad focus in social service reforms, on personalization, which requires starting with the person rather than the service. Yet, another way of thinking about respite is premised on the understanding that 'all relationships are enhanced by time together as well as some time apart' (Armstrong & Shevellar, 2006: 9). The latter also applies to relationships between people with dementia and their family caregivers.

Models of home care and day care traditionally provided in Ireland by statutory organisations like the HSE are also typically offered on a 'take it or leave it' basis, where service users are told 'Here is the service' and asked 'Do you want it?' This traditional approach to respite care for people with dementia and family caregivers has been underpinned by the biomedical model of dementia care. This model has in the past disempowered people, relegating them to a passive status of service recipient.

Traditional models of respite have also tended to distance people with dementia from their community. For example, people in rural towns and communites may be "brought to" day centres often situated at a distance from where they normally live or they are "put into" residential respite care in institutional settings where they generally have to adhere to organisational constraints. The services that have evolved underpinned by this model tend to result in dementia remaining hidden, behind closed doors and not owned by the community. Traditional approaches tend to focus on the illness rather than on the person and on that person's lost ability rather than on retained ability and strengths. Proponents of this model would argue that the experts are the health service professionals and those responsible for medical scientific research (Kitwood, 1997). In this more traditional model, family caregivers can be marginalised. The model is not inclusive of individual or family preferences and tends to cater for groups rather than individuals. The biomedical model tends not to offer choice.

2. PURPOSE OF THE DSWI

Based on a review of the project literature and two meetings with the Old Age Psychiatrist leading the project, the Project Co-coordinator and the Community Mental Health Team (CMHT) involved in the project, a logic model of the DSWI was drawn up (see Table 1), which outlines the objectives of the DSWI, the principles underlying the DSWI developed by the 5 Steps Programme, the intended outcomes of the DSWI and the process by which it would be implemented.

The key purpose of establishing the DSWI was to provide in-home respite supports to community-dwelling people with dementia and their family caregivers. It is well known that dementia can affect the individual's entire life, and if the person diagnosed fails to remain active, engaged and socially stimulated, he/she can become bored, isolated and withdrawn. From the point of view of the individual with dementia, the need for occupation in an activity meaningful to that person was identified as an unmet need in the early stages of the development of the new respite support service. It was recognised that there was a need to provide an individually tailored in-home respite support service which would promote personhood, improve quality of life, enhance social engagement and reinforce self-identity.

Accordingly, in establishing the DSWI, an emphasis was placed on supporting the person with dementia to continue living as normally as possible, a rich and fulfilling life in the community. The focus would be on bringing out the best in people with dementia, focusing on their strengths and interests and giving family caregivers regular and consistent short breaks from dementia care, thereby supporting them in a flexible and responsive manner. Ultimately, the DSWI was designed to help to sustain community care and to ensure that people with dementia remain at home.

Table1: DSWI Logic Model: Objectives, Principles and Intended Outcomes of the DSWI

OBJECTIVES OF THE DEMENTIA SUPPORT WORKER INITIATIVE

To develop and demonstrate alternative models of respite services under the 5 Steps to Living Well with Dementia project that:

- are flexible
- place an emphasis on supporting the person in continuing their ordinary life and to live full lives in their communities, through focusing on their strengths and interests
- support carers in their caring role
- enable people with dementia to remain at home
- make use of existing community services
- enhance integration, collaboration and skill sharing across services, e.g. training to staff and providers
- are sustainable in the long-term
- represent value for money and a cost-effective alternative to existing respite services
- contribute to efforts aimed at changing long-established, complex systems of care delivery in dementia

PRINCIPLES OF THE DEMENTIA SUPPORT WORKER INITIATIVE

- The respite service is flexible
- The respite service is responsive to needs of individual people with dementia and family caregivers
- The respite service is person-centred
- The respite service is client-led, that is, gives person with dementia and family caregiver greater choice and control over supports received
- The respite service is time-limited
- The respite service is delivered by the same care workers (where possible) that are specifically trained in dementia care
- The respite service is easy to access

DSW Initiative is sustainable and provides value for money

INTENDED OUTCOMES

DSW Initiative enhances community care for persons with dementia:

- Persons with dementia are better enabled to meet their personal goals
- Persons with dementia receiving supports have improvements in the quality of life and wellbeing (as perceived by them and as measured objectively)
- Persons with dementia are satisfied with the supports received under the DSW Initiative

DSW Initiative enhances community care of family caregivers of persons with dementia:

- Family caregivers of persons with dementia are better enabled to meet their personal goals
- Family caregivers of persons with dementia receiving supports have improvements in the

quality of life and wellbeing (as perceived by them and as measured objectively)
- Family caregivers of persons with dementia receiving supports are satisfied with the supports received under the DSW Initiative

DSW Initiative is person-centered and individualized

- Supports are client-led, that is, persons with dementia and family caregivers receiving supports can exercise choice and control over their care

DSW Initiative is sustainable and provides value for money

IMPLEMENTATION PROCESSES

Instigation of DSW Initiative

- The Genio Trust provides funding to successful projects
- 5 Steps to Living Well with Dementia develops DSW Initiative based on model of in-home supports developed
- DSW initiative publicized

Planning and delivery of supports under DSW initiative

- Project identifies Dementia Support Workers contracted to existing service providers
- Project provides dementia-specific training to Dementia Support Workers
- Service needs of persons with dementia and family caregivers are assessed by the project
- Project selects people with dementia and family caregivers to voluntarily participate in the DSW initiative
- Project arranges for provision of Dementia Support Worker
- DSW and 'service users' develop an individualized care plan that details supports to be provided under the initiative
- Dementia Support Worker provides supports to person with dementia and/or family caregiver

The 5 Steps Project was well aware that caring for a relative with dementia can be very stressful and without regular breaks, informal caregivers can experience a significant decline in their own health and well-being, which may ultimately lead to burnout. The latter otherwise known as caregiver burden has been identified as one of the main reasons why family caregivers decide to place their relatives with dementia in long-term residential care. It was identified that the new service would address family caregivers' unmet need for regular short breaks (respite) and support from the often intense round-the-clock nature of dementia care. Ultimately this type of respite it was believed could contribute to caregivers being enabled to provide home care for longer. This new respite service also aimed at improving quality of life for people with dementia and for their family caregivers. The service was also designed to address caregivers' information and educational needs.

In summary, the DSWI was designed to provide an individualized and person-centered approach with benefits to be derived by both people with dementia and their family members. The emphasis would be on opportunities for participation in meaningful activities, with a focus on flexibility and therapeutic input. The supports were to be provided to both men and women with either a mild, moderate or severe dementia who were living in their own homes, either alone or with family members. The DSWI would provide one-to-one support to the person with dementia and/or the family caregiver. Many of these people were already in receipt of other either more conventional statutory (HSE) or voluntary services (ASI) services.

The new supports were designed to offer a flexible approach to respite care (see Table 1). People with dementia and their caregivers would generally be offered two hours respite care at home on a once weekly basis over a ten-week period[1]. Following a home-based assessment with a clinical team member of the Psychiatry of Old Age (POA) team and negotiation with both the person with dementia and his/her caregiver, every effort would be made to provide individually tailored supports designed to address both the person with dementia and his or her family caregivers' own unique needs. In this way, the DSWI was an attempt to move away from more traditional, building based respite services to a more personalised form of respite service.

It should be noted that this evaluation was conducted in the summer of 2013, when the respite initiative was in its early stages as it was running for only a few months at this point. Based on the experiences to date and feedback from those receiving the service and others, significant changes have been made to the delivery of the service in early 2014.

3. METHODOLOGY

The approach adopted for this evaluation of the DSWI was primarily qualitative. As the research focused on a small number of families (N=12) in receipt of a new model of

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[1] Initially, this had been offered on an eight-week basis, but was extended following feedback from the DSWI. The amount of support could vary and could be extended beyond ten weeks, where deemed necessary.

supports, a qualitative approach, using an exploratory design, was deemed most appropriate for the task at hand. This also ensured that the experience and views of the service users, the people with dementia and their families, availing of the supports were heard and would be used to inform future development of respite supports. This qualitative approach was augmented where possible and in most cases with quantitative data collected on quality of life and caregiver strain.

3.1 In-Depth Interviews

In-depth interviews, which have been used successfully in other similar research on respite (Carroll et al., 2005) and deemed to be important in intervention research (Zarit & Leitsch, 2001), were conducted with a sample of people with dementia and family caregivers who availed of the DSWI supports. The purpose of these interviews was to evaluate the impact of the DSWI from the perspective of both the person with dementia and family caregivers. According to Zarit and Leitsch (2001), it is critically important to evaluate the anticipated outcomes of an intervention for both the family caregiver and the person with dementia.

In by far the majority of cases at this point in the development of the service, the respite service provided under the DSWI was only available for two hours and was provided on a once weekly basis. However, the time and frequency of support could be varied based on need. The findings presented in this report draw on data collected from 20 interviews with people with dementia (8)[2] and with family caregivers (12)[3] who, during 2013, were in receipt of supports from the DSWI. At the outset it is important to remember, that although in writing, we refer to all family members who participated in interviews as family caregivers, some did not see or define themselves as caregivers. Most of the research interviews were undertaken at least halfway through the duration of the respite support service. A small number were conducted after the ten-week respite support had come to an end. One of the interviews occurred before the supports

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[2] In three of the 12 families, a person with dementia was unable to participate in a qualitative interview and in one other family a woman with dementia chose not to participate in an interview.

[3] One man with dementia interviewed for the study chose not to nominate a family member to participate in a qualitative interview. In one family, two family caregivers chose to participate in a joint interview.

commenced. Interviews were recorded with the permission of participants and transcribed verbatim.

3.2 Quality of Life Scale (QOL-AD) and Caregiver Burden Scale (ZBI)

For the purpose of collecting the quantitative data, two standardized validated scales were used. Logsdon's QOL-AD tool was used to derive a measure of the quality of life of the person with dementia. The QOL-AD is a brief 13-item tool, designed specifically to obtain a measure of the person with dementia's quality of life from the perspective of both the person with dementia and the family caregiver (Logsdon & Albert, 1999). With the participants' permission, the audio-recorder was left running whilst participants answered questions on this scale. The QOL-AD was completed by eight people with dementia and all of the family caregivers participating also completed it. In one family the QOL-AD was completed jointly by the two participating family caregivers. Participants were also invited to expand on or qualify their responses if they so wished. Qualitative responses can be helpful in interpreting quantitative findings (Zarit & Leitsch, 2001), and taping the responses to the QOL-AD meant that when some of these questions prompted participants to reflect on issues relating to the DSWI which had not already been discussed in interview, and allowed for this information to be captured and recorded.

The Zarit Burden Interview (ZBI) was used to measure the degree to which family caregivers perceived their care-giving responsibilities were having an adverse effect on their health, personal and social life, psychological wellbeing and finances (Zarit, Reever & Bach Peterson, 1980). It is a 22-item inventory with each item rated on a 5-point scale, i.e. never, rarely, sometimes, quite frequently, and nearly always. The instrument also asks questions about dependency levels of the person with dementia, embarrassment and anger with the person with dementia, and carers' ability to sustain the caring role for longer. Using the responses from the ZBI, a score is generated for each participant. A high overall score is indicative of a high level of caregiver strain (see Table 2 below). The conventional cut-offs on this scale are 0-20 reflecting little or no burden; 21-40 reflecting mild to moderate burden; 41 to 60 reflecting moderate to severe burden and 61 to 68 reflecting severe burden. The ZBI was administered to all participating family caregivers (i.e. family caregivers in 11 cases).

3.3 Interview Schedule

Following an extensive literature review on the topic of dementia and respite care interventions, discussions with the staff of the 5 Steps Project to establish the respite supports being developed and on offer, and the development of the Logic Model (as presented in Table 1), an interview schedule was designed. The schedule had a particular emphasis on the DSWI and its objectives, principles and intended outcomes. Topics covered in the interview schedule included: (i) how and by whom this service was introduced to families, (ii) the type of service on offer including service recipients' experiences and views of the 5 Steps project staff employed and (iii) the person with dementia's and family caregivers' perspectives about the supports, along with their views on the discontinuation of this service. In addition, the interview schedule sought to investigate the extent to which service recipients were satisfied with the new supports offered. Questions exploring the extent to which the supports helped to delay entry into residential long-stay care were also asked of people with dementia and their family caregivers.

Ethical approval was sought for the project and granted by the Research Ethics Approval Committee, School of Social Work and Social Policy, Trinity College Dublin.

3.4 Profile of Participants

Regarding recruitment of participants and contacts, shared procedures and protocols were developed between the researchers and the project lead and project coordinator of the DSWI. The project lead and project coordinator purposefully selected and then approached a sample of people with dementia and their family caregivers (who had been offered or were already availing of DSWI supports) to ask might they be interested in research participation. If interested, names and contact details were subject to their permission, given to the researcher who later contacted them to further explore. Once the participants had been fully informed about the research and consented to participate[4], an interview was arranged at a time and place convenient to them. All interviews bar one took place in the participants' homes.

As mentioned above, 12 families of people with dementia participated in the research. , These were families of six men and six women with dementia, Two of these men, aged less than 65 years, had an early onset dementia and were being supported at home by their wives. The majority of these people had a mild to moderate dementia. However, there were three families where the person's dementia had now progressed to an advanced or end stage and hence they did not participate in interviews. Each of these three individuals was still living in their own homes and in each case round-the-clock care was being provided and shared between adult children and their own family members. It is important to note that these adult child carers lived apart from their relative with dementia and were essentially running between two houses.

At least one family member/caregiver from each of the 12 families participated in the study. They consisted of five spouses (four wives and one husband), five daughters, one daughter-in-law and one son. In one case a single man with mild dementia who had good insight chose to participate but not to nominate a family member for a research interview. This man lived alone. In all but four cases, people with dementia were living with other family members at the time of the research interview. Some of these people were living in remote rural areas and a small number came from a farming background.

4. RESULTS

4.1 The Organization of the DSWI

The DSWI in South Tipperary was delivered by Community Mental Health Service, an interdisciplinary Community Mental Health Team (CMHT) led by an Old Age Psychiatrist (OAP) (see section 2). Members of the CMHT had experience working alongside each other. Overall responsibility for the DSWI rested with the OAP leading the 5 Steps Project and the South Tipperary Community Mental Health Service. The

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[4] Information sheets and consent forms were drawn up in co-operation with the project lead and project coordinator. The approach taken to obtaining content was process consent.

Project coordinator on the 5 Steps Programme had responsibility for coordinating the DSWI, and worked closely with the Project Lead and the CMHT.

The DSWI co-opted in other support workers. The Dementia Support Workers (DSWs) were engaged by the project to provide home-based supports to people with dementia. Those DSWs recruited were formal care workers already contracted to existing service providers (the ASI and the Carers Association)**.** They were carers with FETAC Level 5 Carer Training. Some had received dementia training from the local branches of the ASI and the Carers Association and had already been Garda vetted. This essentially meant that the initiative was fast tracked; it could build on existing resources and pathways through care were probably more integrated and less confusing for people. All co-opted carers received additional specialist, tailor-made dementia training by the 5 Steps Project to work as Dementia Support Workers under the Initiative. Regular meetings were held with the CMHT and the DSWs.

4.2 Accessing the DSWI

All people with dementia selected for participation in the DSWI had to be registered as patients with the OAP who was responsible for the 5 Steps Project. In response to questions asked about how they first heard about and accessed the DSWI, three quarters of interviewees stated that staff on the South Tipperary Community Mental Health Service had been proactive in reaching out to families, bringing the DSWI to their attention and facilitating their access to it. In the remaining three cases, it was the PHN or GP who referred families to the 5 Steps Project with a view to accessing the DSWI. Therefore, health professionals on the CMHT played a pivotal role in facilitating families to gain access to the DSWI, although participants also learned about the 5 Steps Project through a broader range of sources including the ASI and through hospital services. However, analysis of the interview data revealed the pivotal role of public health nurses, GPs and the ASI in helping families access the programme:

> *It was introduced to me by, em, as far as I can remember, the Community Mental Health Nurse, who contacted me, I think, or, em, the coordinator maybe for the 5*

> *Steps programme... It was mainly both of them who brought it to my attention. [Family caregiver 3]*

> *... our district nurse who is fantastic ... she has been incredible. Now, em, she, she kind of, well she knew anyway the whole situation and it was her, that got the whole thing rolling with the Alzheimer Society and with [the 5 Steps Project coordinator...] [Family caregiver 2]*

> *So it was [the Old Age Psychiatrist] actually who made the suggestion. She's involved with Genio ... [Family caregiver, ST 4]*

4.3 Assessment and Care Pathways

An early holistic assessment emerged as a core feature of the Initiative and this often involved close liaison with Health Service Professionals (HSPs) on the CMHT, to obtain relevant information important in decision-making about suitability for the DSWI. In particular, the close liaison that existed between the HSPs on the South Tipperary CMHT and the project lead and project coordinator greatly assisted in assessing a person's suitability and interest. One daughter whose father was a patient of the OAP commented:

> *following that [the Old Age Psychiatrist] got in touch with the Genio coordinator who then spoke with me, ehm, to see if dad would benefit, ehm, and also through ... the, ehm, community psychiatric nurse, she really did an assessment on dad and really looked what our expectation is and really if dad would benefit. [Family caregiver 3]*

Once initial contact was made, families were approached by the DSWI coordinator who visited their home and informed both the person with dementia and family caregiver about the Initiative. Written information was also provided and detailed advice given about what to expect from the respite supports before identifying a DSW to work with the family:

> *I then liaised with the coordinator and they identified, ehm, a representative to come. We met with the representative; we discussed kind of dad's care, his needs and really what our expectation was from that person. [Family caregiver 4]*

> *[The coordinator] came and just chatted to us and talked us through, you know, what would happen. [Family caregiver 2]*

This early visit was also useful in helping to determine both family caregivers' and persons' with dementia unique needs and in finding out more about the person with dementia's interests and life story.

> *When it was being set up, [the project coordinator] was asking me you know like, what [my husband's] interests were because I think you know a lot of it is, when I say activity based, you know, … they like to do you know activities but [my husband] was farming all his life. [Family caregiver 2]*

After agreement to participate was reached, the Project Co-ordinator arranged for a DSW to visit and meet with the family and come to further agreement about the arrangements. The DSW initially worked with the person with dementia to develop an individualised care plan that detailed supports to be provided under the initiative. Over ten weeks, the DSW provided supports to the person with dementia with an emphasis on supporting the person to continue their ordinary life and live full and meaningful lives at home and in their communities, through focusing on their strengths and interests, whilst at the same time providing support for family caregivers.

Family caregivers reported that the DSWI staff remained proactive in keeping them informed about additional service supports such as day care, carer groups, educational events, the Alzheimer's Café, other respite programmes and exercise classes[5]. This was an important aspect of the programme as many people lacked knowledge about dementia services and were really appreciative of having this key contact person to inform and guide them. One daughter whose family was provided round-the-clock care

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[5] As the project evolved, the 5 Steps Project set up some carer meetings and organized a physical exercise programme, which some of the interviewees attended.

for her mother reported that the DSWI staff member made the family aware for the first time of a day care service, which their mother then started attending. Another family caregiver whose experiences reflected that of several others explained:

> *She invited us to, ehm, partake in Keep Fit classes [...] with another group of people with similar problems and that kind of was something to look forward to. [Family caregiver 7]*

4.4 Flexibility

Two-thirds of the family caregivers described the programme as being flexible and reported how it accommodated their complex and often changing needs. For example, in one case, a person with dementia was admitted to hospital during the course of the ten-week programme, when the service obviously had to be discontinued. Interestingly, in this case, the family was reassured that once their relative was discharged from hospital, the DSWI programme would recommence.

Consistency of staff (the same staff member involved throughout the ten weeks) was an aspect of the service hugely appreciated, but in one unusual case, where after four weeks, a DSW left to pursue further education, a decision was made that a new support worker would start afresh and provide supports again for a full ten-week period. In this case, the project coordinator undertook a home visit with the new staff member to introduce her to the family for whom the service had stopped.

In another case, where a daughter lived apart from her father (who had a severe dementia) and was essentially running two homes, the DSWI hours were extended to provide some weekend respite coverage. Two other families had their respite hours extended over to weekends (ST 4 and ST 11). This high level of flexibility was particularly important for adult children who worked and/or had other caring commitments:

> *She is very flexible, very flexible, I had her (telephone) number, she had my contact number. We're both very flexible actually but, ehm, she was, ehm, very diligent. [Family caregiver 4]*

> *Interviewer: And were they flexible in the times that they could offer you? – Family caregiver: Oh yeah, we came to a compromise whichever suited all of the family. [Family caregiver 12]*

Indeed the flexibility of the programme was a feature also important to people with dementia, many of whom exercised control over how the service was delivered to them:

> *Oh, it was [flexible], yeah, it was, it was, yeah, it was arranged and if-if I couldn't (have her come), I contacted them and said, well, look, can we leave it for another two hours or whatever, you know, or they'd, or they'd be doing something when we would be away or anything like that, so, you know [Person with dementia 7]*

4.5 Effectiveness of Respite Services in Meeting the Needs of Persons with dementia

The data showed that much time and effort was invested by DSWI staff into getting to know the person with dementia's interests, life stories including prior occupations and in linking activities offered during respite to individual biographies. In fact all of the family caregivers and several people with dementia commented very positively about the extent to which the DSWI supports offered such a diversity of individualized, meaningful and pleasurable activities designed to match peoples' own life time interests. Activities offered included art work, painting, jigsaws, coloring, reading, music, gardening, card playing, shopping trips, visits to museums and life story work.

As mentioned, the approach to respite was entirely flexible and tailored to individual needs and preferences, offering choice, empowering and promoting individual autonomy. Activities were made available within the homes but in most cases if desired by the person with dementia activities could take place outside the home. Activities were delivered by staff trained to facilitate these activities according to the principles underpinning the initiative on a consistent and strictly individualised basis.

4.5.1 Choice

Choice was most important to both family caregivers and their relatives who were very appreciative of the fact that their respective interests were always respected.

> *She would come and she would say like … would you like to play cards or … would you like to do a bit of art, but [he's] not artistic or nothing you know … or would you prefer just to sit and chat… [Family caregiver 2]*

> *Definitely he would, he'd have a choice, yeah, and definitely his interests were looked at and yeah. [Family caregiver 7]*

> *When we were doing paintings, she said to me. "I leave it to you yourself now for the colour" or, you know, something like that and she gave to me different … there'd be different (colours). [Person with dementia 8]*

As stated, activities were carefully chosen to be meaningful and in most cases involved a continuation of normal lifelong hobbies such as gardening, baking, football, or simply just going off to the shops.

4.5.2 Linking Activities to Life Stories

Interestingly, there were two cases where the person with dementia was supported to recommence prior hobbies, which because of the dementia they had had to stop probably due to fear or lack of confidence. One of these was a woman who could no longer go outdoors alone but the DSWI staff member now accompanied her into her garden where she took a great interest in her plants and flowers and accordingly resumed her gardening interests. The latter was very important to her quality of life.

In another unusual case where the man with dementia had been a former marathon runner, he was encouraged by a staff member of the 5 Steps Project to resume running, an activity he clearly enjoyed:

> *That was the big thing that sticks out for me… I didn't go straight back into it (running) but I suppose he (the DSWI staff member) encouraged me and eventually I did (return to running)… as I said to you, the half an hour or the hour you know … that was very important. I used to run you know, running was big at the marathons. [Person with dementia 7]*

4.5.3 Developing New Skills

In yet another case, a woman with dementia who enjoyed handwork especially knitting but who had to relinquish this hobby because of her dementia (reading knitting patterns became too complex), was encouraged by the DSW to take up artwork, an activity she clearly enjoyed. Commenting about the new hobby she had started to enjoy since meeting the DSWI worker she said:

> *I loved it (painting) because see I used to knit and I could knit anything but now I can't follow the pattern, so that was a, a terrible drawback. So all I'm doing now is squares and, eh, so when she came I was delighted that I could, I could do the painting and I didn't think I could […] I used to see people painting but it never occurred to me to do it, no, no, no. It was great. [Person with dementia 10]*

4.5.4 Person-Centered Interaction

For those with a more severe dementia, it was simply the company of the DSW and the one-to-one interaction that the DSWI afforded that was highly valued:

> *We felt that even for them (DSW) to come and sit with dad to give him a drink, to give him some yogurt, ehm, to play music [… did really help us as the carers]. [Family caregiver 4]*

It's just companionship, really and just a little bit of motivation. [Family caregiver 10]

We have a lady come here on a Tuesday and a Thursday, and she will talk to [him], she will take him out wherever he wants to. She wanted to take him to the museum the other day to see the new [exhibition] that was following the caravan show and various things. [Family caregiver 9]

4.5.5 Supporting Autonomy

The rich narratives about the type of activities that the DSWI provided reflect the key role support workers played in motivating persons with dementia and in promoting their autonomy, independence and confidence. For example, in one case, a man with mild dementia was helped to become more independent in managing his finances including banking on his own. This was a great source of satisfaction for him and clearly heightened his self-esteem, sense of independence and quality of life.

4.5.6 Effectiveness in Meeting the Needs of Family Members

The DSWI programme was also effective in meeting the needs of family caregivers. Apart from being very satisfied with the individualised and meaningful respite activities provided to their relatives by skilled home support workers, the DSWI was also highly valued by family caregivers, many of whom had very limited free time and cherished the opportunity the couple of hours respite afforded them through this Initiative. Family caregivers gave powerful examples of how the programme helped to relieve them from the strains and stresses associated with caregiving. Several reported that through the programme they felt supported in their role as caregiver both practically and

emotionally. The respite programme was also designed to provide family caregivers with information and advice on dementia-related topics and many family caregivers commended the programme for providing them with much-needed advice and information about caring. A key benefit was that family members believed that the project co-ordinator was very approachable and was available on a flexible basis for practical psychological or emotional help in caring.

In addition, through the DSWI they were often connected to other community-based social and health care services that were valuable. Family caregivers claimed that the programme inspired them and helped build their confidence as caregivers. In particular, they felt that the programme valued their input as 'partners in care'. They welcomed being actively involved in decisions regarding their relative's care and this inclusive partnership approach was clearly important to them. Family caregivers' needs were also met in terms of the ethos underpinning the DSWI. They felt that the programme was truly person-centred and therapeutic, which they associated with improved levels of quality of life for their relatives as well as themselves. Another way in which the DSWI accommodated family caregiver support needs was to, whenever possible, adapt to carers' and their relatives' changing circumstances. For example, in some cases, the DSWI was extended to two visits per week, longer hours and/or beyond the ten week period to satisfy family caregiver's need for more extensive support.

The DSWI also in some cases afforded carers the opportunity to join support groups and feel less isolated or to have a little bit of quality time to themselves. The words of one woman whose husband had dementia were re-echoed by several others. Commenting about the supports she said:

> *Respite is a couple of hours, em, and to know that he's here, that there's someone with him that you know, he's being stimulated and that is just the relief , that is incredible you know, it really is I have to say knowing that ... because its only whenever your freedom I suppose has been taken away from you. You know I run into [names the nearest town] for five minutes and back again, you know, but to go for a couple of hours you know, I wouldn't do it. [Family caregiver 2]*

4.5.7 Validating Concerns

In another case where a couple lived in isolated circumstances and the wife was coming to terms with the changes she noticed in her husband (diagnosed with early onset dementia), she described how the DSWI helped validate her concerns. The DSW helped her to realise that the behaviors she was witnessing were the early manifestation of a neurodegenerative illness. She said:

> *Sometimes I say to myself "Is it real? Am I making it up?" Nobody knows this because [he] would meet people and he's fine and he's short and so her [DSW] being here for the two hours I was able to say to her "What do you think?", you know, and she was able to reflect back to me, yeah, she'd notice this all and it kind of supported me in that like I wasn't just imagining it or getting kind of just too focused on it. [Family caregiver 7]*

4.6 Participants' Perceptions of DSW Staff

4.6.1 Communication Skills and Professionalism

The DSWs were described by family caregivers and by some people with dementia as being experienced, professional and having excellent communication skills. Family caregivers were particularly impressed by the DSWs' ability to listen to their relative, to attune themselves to their relatives' sometimes complex emotional states and to be discreet. Two daughters commented:

> *She just came across as being very professional, obviously had a very good background, ehm, in the sense from a carer's perspective and, ehm, very confidential as one thing that really struck me because she was living quite local but she was very, very discreet. [Family caregiver 4]*

> *She is a very nice and very pleasant girl, and she's very experienced and [...] she knows her stuff [...] she, eh, engages well with my mother and she's gentle and soft-spoken and, you know, that all makes a difference. [Family caregiver 12]*

Similarly, persons with dementia felt they could discuss private concerns and interests with the support worker, whom they perceived as being very respectful and trustworthy. A man with dementia was most articulate in summing up the DSW's unique skills and sensitive easy-going approach when he said:

> *She was easy to talk to, you know, eh, I always wondered what'll I have to say today to her [laughs] or, eh, you know, ehm ... like, the.. you know, that would be wonderful, you know, that'll be wonderful good qualities, you know, like, I think, you know, and there was no pressure as such, you know, I didn't feel any pressure and that I could say what I had to say. [Person with dementia 7]*

4.6.2 Consistency

A key element of the new model of respite support that made it markedly different from previous respite service models was consistency. In other words, the same home support worker visited every time and worked with the person with dementia and family caregiver over the duration of the service. This was viewed as essential given that it takes time to build up a relationship with a care worker. This principle of consistency was rigidly adhered to in order to enable the relationship between the person/support workers to develop gradually and naturally.

As stated earlier, consistency in service delivery was something highly valued and three-quarters of the caregivers specifically talked about the fact that their relative with dementia had the same support worker for the entire duration of the ten-week programme. They believed this high level of consistency was important for establishing trusting relationships and a positive rapport with the person with dementia:

> *It just so happened that she [support worker] also works in [a DCC] so Mam knew her so she was very happy with that then and they suggested that she would come back again in August for ten weeks and she was quite happy with that because she knew her. [Family caregiver 3]*

Persons with dementia's commentaries revealed how quickly and deeply they bonded with 'their' support worker and how much most of them looked forward to the visit.

> *She was brilliant, she was brilliant, yeah, I'd be waiting for the day for-for her … uh, sure you… to the day that she to the day that she was coming you were really looking forward. For the day you'd know that would be coming, you wouldn't be, you wouldn't be disabled you know…we're always laughing. She'd put you in good humor. [Person with dementia 8]*

To summarize this section, the qualitative data show that both family caregivers and persons with dementia perceived the DSWs to be competent and skilled in interacting and communicating with the person with dementia; in respecting their individuality and values and in enhancing their psychological wellbeing. It is interesting that these are staff characteristics shown to be critical to establishing therapeutic and truly person-centered relationships with persons with dementia (Downs & Bowers, 2009; Kitwood, 1997; Bamford, 2013). The findings support UK research on community support services undertaken by Challis et al. (2010). The latter reported that family caregivers expressed a strong preference for consistency in home care services for their relative with dementia and in having the same care worker visit throughout. The personal and professional qualities of DSWs seemed to matter a lot to the participants and arguably were an important factor in their positive evaluation of the initiative. This is significant as caregivers' confidence in the quality of staff employed has been found to be an important factor in the take-up of respite services (Bruen & Howe, 2009).

4.7 Care Needs and Formal Support Services

Although the interview schedule did not attempt to collect data about the type of caring/tending tasks undertaken by family caregivers, there was evidence throughout the research interviews that many of these caregivers were providing extensive, sometimes around-the-clock, care to their relatives, several of whom manifested dementia-related behaviors that can be challenging for family caregivers and for formal care workers such as sleep disturbance, wandering, apathy, hoarding, repeated questions, hallucinations, incontinence and agitation/aggression. Several talked about the fact that their relative could not be left alone and how they needed to be on the alert at home to situations which could otherwise be potentially dangerous or place their lives at risk.

Some of these caregivers were older themselves and several especially those in the oldest age groups (i.e. 80+ years) did not enjoy good health. For example, one octogenarian who cared for her husband, also in his late 80s, had had a stroke several years earlier and had been left with residual and ongoing health problems. She was also partially deaf and had some visual impairment due to cataract problems. Another woman caring for her husband had had two episodes of cancer, which required chemotherapy.

Some of the younger caregivers who lived apart from their relatives had multiple care/work roles and were essentially running two homes. In one exceptional case a family who provided an extremely high level of care for their mother with a severe dementia reported how they had to undertake "shift work" to ensure this woman remained safe and adequately cared for at home. In order to sustain home care, input was required from several different family members, the daughter, her two brothers and her sister-in–law and two grandchildren. This family was concerned about the cost of long-term care and commented that through the DSWI, they were introduced to a Day Care service that their mother now attended, but that this too incurred some additional costs.

4.8 Other Formal and Informal Respite Support

Despite the high level of care required, families tended to receive very limited formal support through the more traditional statutory and voluntary organizations. The majority of the participants in this project had availed of other forms of respite care, mostly based in day care centres. However, at the time of interview, only six of the 12 families had relatives with dementia attending a day care centre. Some people with dementia interviewed had attempted to use day care in the past but had been forced to reduce hours of attendance or had chosen to discontinue its use altogether. The data showed that day care was not always suitable for a variety of reasons, including the absence of transport, the individual's own resistance to getting ready to attend, - *He'd get ready to go but when the time comes ... no. [Family caregiver 1]*, lack of energy, and at times the lack of fit between day care activities and individual interests. The latter was particularly evident amongst the men with dementia in the sample. Family caregivers for the most part were tolerant and accepted their relatives' decision or refusal not to attend day care, but in keeping with the literature (Robinson et al., 2012) some caregivers felt somewhat frustrated about this.

The more conventional day care services were largely described by participants as mainstream and inflexible, catering for larger numbers of more diverse groups of people. Traditional models of day care also meant that caregivers and their relatives had to adhere to rigid time schedules such as a set time of arrival at opening hours and a cut-off closure time, i.e. their relatives having to be collected by a certain time. Day care took place at a venue situated away from the person's home and indeed sometimes away from the person's parish.

The vast majority of participants in this study lived in rural and sometimes remote communities where not only lack of day care centre availability but also the absence of day care transportation posed additional challenges. Getting to and from the service necessitated the availability of transport. For example, in one unusual case where the caregiver reported that she brought her relative to a day care centre once a week, the latter was situated in a town situated 50 kilometres away from where this family lived. Several of the participants gave powerful examples of the limitations of this type of conventional service including the lack of fit between individual interests and day care activities, the absence of transport and the decisions to withdraw from going on the day in question due to person with dementia's fatigue. In contrast, the DSWI overcame several of these limitations by virtue of 'bringing the service to the person' rather than expecting him/her to 'come to the service' (such as commuting to and from the day care centre). It challenged the generalist service-led as opposed to needs-led "building-based" approach to respite (see page 8).

Mainstream respite also tended to offer group as opposed to individualised activities. In contrast, the DSWI was individualised and flexible and this meant that the service offered was responsive to unique needs and interests. Findings from this study revealed how complex and diverse people's preferences and needs were, and how essential it was therefore to offer one-to-one care alongside traditional respite services in order to provide a truly person-centred service. The DSWI also looked upon families and people with dementia as experts and equal rather than as passive service recipients. Their views, as the data has shown, were taken into consideration in the shaping of the service delivered and this was an innovative element of the programme that would not normally be part of more mainstream respite services. Being embedded in the person's immediate home environment as well as his/her local community also helped the programme link families with other community-based supports such as self-help groups, friendship services and primary care. This strategy helped enhance the amount and quality of supports for community-dwelling families.

Whilst there were examples from the study of person-centered care being provided at Day Care Centers, it seems it was not always possible for day care staff to tailor activities to address clients' respective needs. A small minority of families seemed obliged to employ their own private home help support as a type of respite:

> *But we do have a home help outside any scheme at all, I just have to pay it … and it's great, every Tuesday afternoon, and Friday afternoon I'm free. [Family caregiver 5]*

Others relied heavily on informal support provided by family members, usually adult children either overnight or at weekends.

> *the family came and … our daughter… and our son came two different weekends to let me off duty, yes…… but they can't do this regularly because they have families of their own, yeh. [Family caregiver 5]*

Residential respite emerged as a service less frequently used compared with day care and those who used it were more likely to be families whose relatives had a severe dementia. Interestingly, these families believed residential respite provided much needed relief and served to enable family caregivers continue to provide home care for longer. Family caregivers, however, reported that availability of this type of service was very limited, which coincides with the views and experiences of the staff on the 5 Steps Project.

4.9 The DSWI vis-à-vis Traditional Models of Respite Services

As already argued the DSWI represents a shift away from the more traditional model of respite service to a new model whereby supports are individualised for the person with dementia and the family caregiver (see Table 1). The Genio respite programme was underpinned by a social/disability model of dementia. The model of respite piloted was new, flexible, offered choice, was person-centred and creative when compared with other more traditional models available through the HSE, the Alzheimer Society of Ireland and private providers. As shown earlier, The Genio respite programme was shaped and informed by discussions with the key stakeholders including health service professionals and family members.

The model gave voice to the individual, encouraged him/her to be an active participant in decision-making and provided opportunities for relationship building and to some extent social inclusion within given communities. The model was a lot more flexible (e.g. families had a say regarding the timing of their respite) and individualised compared with conventional models. It empowered the person with dementia and the family caregiver, who were seen as experts and who along with the service provider could together decide on what precise form of respite care best suited their overall circumstances. In other words, people did not fit into what service providers considered as appropriate for them, but rather they themselves helped to shape the type of service they ultimately received. Findings from the DSWI showed that the programme was clearly successful in implementing these principles.

4.10 The DSWI and Need for Hospital Care

Another important question raised by this evaluation is to what extent respite care provided through the DSWI helped to reduce the need for hospital care? In answering this question, due consideration needs to be given to the main reasons why people with dementia are admitted to acute care and to the overall health profiles of the client group, both in terms of their cognitive and physical health. Consideration should also be given to the level of strain family caregivers were experiencing (see section 4.12) and to the other roles and responsibilities they had at the time.

Since most of the participants with dementia availing of this new respite programme had either a mild or moderate dementia, they were unlikely to have acute health problems which might warrant a need for hospital care in the immediate future. In fact the majority of research participants in this group were in good physical health and none at the time of interview was exhibiting very serious challenging behaviours. Only two men (both octogenarians) needed hospital care during or immediately before the programme commenced but interestingly in both cases, their health problems which warranted acute care were unrelated to their dementia. One had chest pain and circulatory problems whilst the other had a foot injury. Secondly, and based on the Zarit Burden Interview (ZBI) scale, most of these family caregivers were only mildly to moderately distressed because of caring. If hospital admissions occurred (either before or at the time of interviews), they were for reasons unrelated to the dementia and the respite programme. Overall it needs to be emphasised that the discussion here is more speculative than evidence-based as family caregivers failed to comment on whether the programme made a real difference to their relatives' need for hospital care.

4.11 The DSWI and Need for Long-Stay Residential Care

By far the majority of the caregivers interviewed for this evaluation also clearly wanted to continue providing home care. For example, in response to the question asked "do you wish you could leave the care of your relative to someone else?" seven out of eleven replied no. In response to another question asked "do you feel that you will be unable to care for much longer?" more than half claimed that they rarely or never felt like this. As the interview data suggest, most people with dementia were only experiencing the mild to moderate stages of the illness and although some exhibited challenging behaviours (see section 4.10), nobody's behaviour was such that this would have warranted more long-stay residential care. In other words, none of these men and women was sufficiently violent or aggressive or manifested other such serious challenging behaviours such as paranoia, delusions or dangerous behaviours which may have placed their own lives or their carers' lives at risk.

There were a few exceptions where the data suggested that these carers were at a closer breaking point. One such example was a family where between various relatives 24-hour care was provided. In this case, the primary care role was shared by two family members, one of whom had health problems, was under enormous pressure and had the highest Caregiver Burden score amongst the sample. In this case, hours of respite had already been extended through the DSWI since the time the service first commenced.

These findings resonate with existing literature on the topic. For instance, a US study found that family caregivers of people with dementia who utilize home-based supports earlier in their 'caregiving career' are more likely to maintain their caregiving roles for longer (Gaugler et al., 2005). In this context it would be very interesting and valuable to attempt to follow those participants in this study up over time. One review of evidence related to in-home respite services found it difficult to assess its impact on reducing or delaying entry into long-term residential care (Arksey et al., 2004). In summary and in order to answer the above question more thoroughly, more information collected over a longer period of time is needed to shed light on the associations between this specific type of intervention and how it might help to delay or reduce the need for long-term care.

4.12 Caregiver Strain

As shown through the rich narratives, a few family caregivers were highly stressed and several were both emotionally and physically exhausted from the high level of care that was required. As mentioned in the methodology (see section 3), the Zarit Caregiver Burden Interview (ZBI) comprising of 22 questions and designed to measure caregiver burden was administered to all participating family caregivers.

Results (see Table 2) show that the mean burden score (range = 20 to 36) for participants in this sample was 32, reflecting the fact that the majority (7 out of 11) of these family caregivers were either mildly or moderately stressed. Interestingly, an exception was an unemployed man who had the lowest caregiver burden score (ZBI=8). Despite this, the carer, an adult son, reported he would welcome more support with caring and although he provided care to his parents both of whom had dementia[6], he seemed not particularly stressed. This was the only case where an adult child was caring for a parent and co-residing with them.

There were three cases (ST 7, ST 9 and ST 11) where family caregivers' scores on the ZBI were 40 or over, suggesting that they were experiencing more severe stress. Analysis of transcripts showed that one of these carers was a woman whose husband was diagnosed with early onset dementia; another was an older woman in very poor health who cared for her husband. She believed that caring was adversely affecting her own health. In the third case where the highest ZBI score was achieved, the caring role was shared among a number of adult children and grandchildren. It is interesting in this latter case that the woman's illness had been kept disguised by her husband until his death some 12 months earlier when the family then became aware of this. It is important to note that caregivers in two of these three cases had asked for more respite.

Our findings are in accordance with those reported in the literature, demonstrating that while the DSWI was a source of great support to family caregivers, it had the potential at times to reinforce the need for further periods of respite at increasing intervals and durations (McNally, Ben-Shlomo & Newman, 1999).

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[6] At the time of research interview his father was in residential respite.

Table 2: Caregiver Burden and Responses to Zarit Burden Interview

Question	Never/ Rarely	Sometimes	Quite frequently /Nearly always
1: Do you feel that your relative asks for more help than he/she needs?	9	1	1
2: Do you feel that because of the time you spend with your relative that you don't have enough time for yourself?	3	4	4
3: Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?	3	2	6
4: Do you feel embarrassed over your relative's behavior?	9	2	0
5: Do you feel angry when you are around your relative?	6	4	1
6: Do you feel that your relative currently affects your relationships with other family members or friends in a negative way?	8	1	2
7: Are you afraid what the future holds for your relative?	0	4	7
8: Do you feel your relative is dependent on you?	2	1	8
9: Do you feel strained when you are around your relative?	5	4	2
10: Do you feel your health has suffered because of your involvement with your relative?	6	4	1
11: Do you feel that you don't have as much privacy as you would like because of your relative?	6	2	3
12: Do you feel that your social life has suffered because you are caring for your relative?	5	2	4
13: Do you feel uncomfortable about having friends over because of your relative?	8	2	1
14: Do you feel that your relative seems to expect you to take care of him/her as if you were the only one he/she could depend on?	4	0	7
15: Do you feel that you don't have enough money to take care of your relative in addition to the rest of your expenses?	7	2	2
16: Do you feel that you will be unable to care of your relative much longer?	6	3	2
17: Do you feel you have lost control of your life since your relative's illness?	8	1	2
18: Do you wish you could leave the care of your relative to someone else?	8	1	2
19: Do you feel uncertain about what to do about your relative?	4	2	5
20: Do you feel you should be doing more for your relative?	7	4	0
21: Do you feel you could do a better job in caring for your relative?	8	1	2
22: Overall, how burdened do you feel in caring for your relative?	5	2	4

4.13 Correlates of Burden and Home Care Continuation

As stated earlier, family caregivers were by and large extremely committed to providing home care for their relatives. Most claimed that their relative was dependent on them; several needed help with all their Activities of Daily Living (ADLs) and some needed careful monitoring in case they might leave the house unaccompanied or get into harmful situations at home. Despite the high level of care required, most family caregivers wanted to continue to provide home care.

4.13.1 Anger

In response to specific items on the ZBI, the majority of caregivers reported that they were not angry with their relative but rather they were angry at the situation in which they found themselves. Most had sympathy for their relatives whom they tended to describe as frustrated, as a result of not being able to do the things that had been so integral to their earlier lives. In this context the loss of a driver's license was the source of much frustration for people with dementia, as it tended to symbolize the loss of independence.

4.13.2 Embarrassment

Most family caregivers were not embarrassed about their relatives' behavior and believed that caring had not adversely affected family relationships. A small minority (daughters of people with dementia), however, challenged this view and their comments illustrated very vividly how caring could adversely impact on other family members including sibling and intergenerational relationships.

4.13.3 Home Care Sustainability

During the in-depth interviews, the majority of family caregivers, when asked the question about the possibility of relinquishing home care, claimed that this was not likely at this particular point in time. There were five family caregivers, however, who reported that they might not be able to care for much longer.

One of these was an older woman whose husband had only recently been diagnosed. This woman did not enjoy good health and had mobility problems – *that's a difficult one… because I don't know my health is going, you know what I mean, with these feet and everything [Family caregiver 9]*. She had the third highest ZBI score in the sample. During the interview she talked at length about her husband's frustration with his situation, particularly his having to quit driving, his refusal to take taxies or use a walking stick and his bad temper. She reported that sometimes she was frightened of him – *I'm afraid some days… I'm afraid to say anything too much, I have to be careful [Family caregiver 9]*.

There was only one case where family caregivers[7] acknowledged that they frequently thought they might no longer be able to provide home care. The family caregivers here had the highest ZBI score at 59. This was a very complex case where the family had introduced a roster system for family members to take turns staying over in their mother's home and the primary care role was jointly held by a daughter and daughter-in-law, both of whom felt under enormous strain. The daughter-in-law carer said:

> *… because their [DSWI's) whole aim was to keep her out of there [long term care] but the longer we are doing it and the more we can see changes in her we do, we've kind of come to the realization we're not going to be able to do this forever. We're not going to, we're definitely not going to … [Family caregiver 11b]*

These two cases highlight the fact that the needs of co-resident and non-resident caregivers (most often adult children) can often be quite different.

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[7] This was the only case in the research where two family caregivers agreed to be interviewed and where the Zarit Burden Interview was conducted jointly.

4.14 Quality of Life

As stated in the Methodology section (see page 9), the Logsdon Quality of Life Scale (QOL-AD) which comprises 13 questions designed to measure the quality of life (QOL) was used in this study. The scale measures QOL of the person with dementia, as rated both by people with dementia and their family caregivers. It examines quality of life across 13 domains at a particular point in time. These domains are: (i) mood, (ii) energy levels, (iii) physical health, (iv) memory, (v) living situation, (vi) relationships with family, (vii) relationships and friends, (viii) ability to do things around the house, (ix) ability to do things for fun, (x) marriage, (xi) self as a whole, (xii) money and (xiii) individual's own overall assessment of their life as a whole.

A 4-point Likert scale is used in response categories for each question: Poor, Fair, Good or Excellent[8]. A high score on this scale is indicative of a very good quality of life and conversely a low score suggests a poor quality of life. Persons with dementia and family caregivers were asked to respond to these questions and to elaborate on topics relating to quality of life that had not already been discussed during the interview.

This section to follow presents findings on responses by eight persons with dementia[9] and 11 family caregivers to the QOL-AD scale. Table 3 presents people with dementia's self-ratings on quality of life and Table 4 presents family caregivers' ratings of their relatives' quality of life. For the purpose of this report only broad trends on quality of life are reported here.

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[8] The scale does not address issues such as independence, normality and confidence, issues that as the qualitative data has shown were very important to several of these people.

[7] Three people with dementia were unable to complete the QOL-AD themselves due to the severity of their dementia and in one family a women with dementia chose not to participate in the study.

Table 3: Responses of persons with dementia to QOL-AD (N=8)

QOL Domain	Poor	Fair	Good	Excellent
Physical health	0	4	3	1
Energy	4	1	3	0
Mood	1	3	4	0
Living situation	0	0	5	3
Memory	3	5	0	0
Family	0	0	4	4
Marriage	0	0	4	3
Friends	0	1	6	1
Self as a whole	0	4	3	1
Ability to do chores around the house	1	3	3	1
Ability to do things for fun	1	4	3	0
Money	1	3	4	0
Life as a whole	1	1	5	1

The QOL-AD scores ranged from 24-39 from the perspective of people with dementia, with an average of 34 and a median of 34.

Table 4: Responses of Family Caregivers to QOL-AD (their perceptions of their relatives' quality of life)*

QOL Domain	Poor	Fair	Good	Excellent
Physical health	2	5	2	2
Energy	7	3	1	0
Mood	2	5	4	0
Living situation	0	1	9	1
Memory	7	3	1	0
Family	1	1	6	3
Marriage	1	1	4	5
Friends	4	2	4	1
Self as a whole	3	4	4	0
Ability to do chores around the house	6	4	1	0
Ability to do things for fun	4	5	2	0
Money	2	4	3	2
Life as a whole	2	7	2	0

* **Numbers of family caregivers per category across 13 QOL domains**

The QOL-AD scores ranged from 22-34 from the perspectives of family caregivers, with an average of 29 and a median of 30.

Several interesting findings can be observed from these tables. First, in keeping with the literature (Banerjee et al., 2009), the quality of life ratings reported by people with dementia were overall more positive than proxy ratings as reflected in the fact that the mean quality of life score, reported by people with dementia was 34 (range = 24 to 34) and this compared with a mean score of 29 (range = 22 to 34) reported through proxy accounts.

Regarding items on the scale, findings show that people with dementia tended to rate their memory, energy levels, and ability to do things for fun as only poor or fair. In contrast, family, marriage and friends were generally rated by them far more positively and were important components of their quality of life. In comparing proxy accounts with individual ratings, it can also be seen that for the following domain items - memory, ability to undertake chores around the house, and life as a whole - family caregivers' ratings were considerably more negative than people with dementia's own ratings. Interestingly, proxies tended to rate their relatives' physical health, family, marriage and friends higher than other items on the scale.

4.14.1 Insight

Whilst answering questions on the QOL-AD, several participants expanded on topics introduced. The qualitative data (not shown here) also revealed how the majority of these people with dementia had good insight and most were aware of their memory problems, some indeed speaking quite openly about how much the latter frustrated them. Indeed, a small minority had extraordinarily high levels of insight. One woman [ST 5], for example, who enjoyed a good quality of life (QOL-AD =39) despite having arthritis and feeling frustrated because of her dementia was very concerned about the impact her dementia was having on her husband. In particular she worried about the fact that because of her illness he had to give up hobbies she knew he really enjoyed. This same man had one of the lowest caregiver burden scores in the study.

Another woman despite her cognitive impairment, when asked for her opinion on the ten-week duration of the programme, commented that the latter was probably a good amount of time as it took time to build up a rapport with strangers. One man spoke openly about his hallucinations and how they concerned him.

4.14.2 Enjoying a Good Quality of Life Despite Dementia

Despite the fact that most of these people with dementia rated their memory, energy levels and physical health as either fair or poor, interestingly most remained active. Several, as a result of the DSWI, were being supported to remain socially engaged and to participate in activities and this clearly contributed to their wellbeing and to an improved quality of life.

For example, a woman whose husband had dementia, spoke openly about how rapidly his short term memory had deteriorated – *I mean this [dementia] has just sucked the life out of him … and you would be chatting and two minutes later its [memory] gone. [Family caregiver 2]*. She also talked about how the DSWI was now supporting them through life story work to assemble family photographs for reminiscence purposes. This activity was something they both enjoyed:

> *what she's actually doing is a little book, a time line book… we had to get out photographs and that was great…. this is something we'll have [as his dementia progresses]. [Family caregiver 2]*

She later went on to say "*we can't praise them enough*". Her views were corroborated by her husband who said: "*I would be happy after spending time with (the DSW). I would yes, we would have a lot in common." [Person with dementia 2]*.

4.14.3 Contribution of DSWI to Person with Dementia's Quality of Life

For others, the DSWI, as demonstrated earlier, enabled them take up new hobbies or be motivated to rekindle their life-long interests (examples include running or gardening) or be supported to gain confidence and independence, something which clearly contributed to their quality of life:

> *Interviewer: What would you see as being the biggest benefit of participation in the programme….? – Person with dementia: Well, the self-esteem and my fitness levels, you know, which would be very important to me. You know, because like fitness*

> *was something you know that from an early age was very important, you know. [Person with dementia 7]*

> *Interviewer: Do you think it [DSWI] boosted your mood? – Person with dementia: It did, it did without a doubt, yeh, because we established a relationship and we're always laughing. She'd put you in good humor. She was brilliant. [Person with dementia 8]*

Despite having spoken about low energy levels, physical fatigue and poor mobility, these people with dementia seldom complained during the interviews but rather claimed that their life on the whole was good. Their narratives clearly revealed an overall contentment with life and with their being able to get on with routine things, which gave them pleasure.

A man who lived on his own talked about the DSWI in the context of his overall life. He said:

> *She came out to me for ten weeks, we've done a lot, we sorted flowers on occasion, we walked on a few occasions, we played cards, we've done some drawings … she was brilliant [Person with dementia 8]*

4.14.4 Improvements Noted in Family Caregivers' Quality of Life

Likewise, several of the family caregivers were very articulate in identifying how the DSWI had contributed to improving their own (family caregivers') quality of life.

> *Interviewer: So, you feel that you have better supports since you have been introduced to the Five Steps programme? – Family caregiver: Oh definitely, yes, definitely. [Family caregiver 2]*

> *Interviewer: Do you think it made any difference to you in trying to support [your wife] having those two hours…? – Family caregiver: Eh, it did yes, yeah. [Family caregiver 5]*

> *Of course it has [made a difference and given relief] for me [with emphasis]. [Family caregiver 9]*

> *It gave me confidence, you know, it gave me confidence which was the biggest thing and that I wasn't alone [...] it has taken a lot of the fear away, you know, ……I suppose to be able to talk about it, you know, and it has created an interest, you know, yeah. [Family caregiver 7]*

4.15 Satisfaction with the DSWI Programme

So far the data has provided valuable insight into the lives of these people diagnosed with dementia and their family caregivers and how they coped on a day-to-day basis with the challenges that living with dementia posed. Findings have shown the high level of care and support some people with dementia required and the limited amount of formal support families received from statutory or voluntary services. Informal support, i.e. assistance in caring from other family members, was not always available due to adult children's own circumstances or commitments. One example of this was a younger man with early onset dementia whose two sons were studying and lived away from the family home and in another case two adult daughters lived abroad. Primary caregivers also seemed acutely aware of their childrens' own familial obligations and commitments and for this reason were disinclined to place demands on them. The data provide compelling evidence of the value of the DSWI weekly supports, particularly in terms of its flexibility, its person-centered ethos; how it afforded caregivers a break from the duties of dementia care and in particular how it promoted quality of life, be that temporary or more long term.

Indeed, when asked specifically what difference the Initiative made to their lives, several family caregivers commented on the quality of care given to their relatives (see section 4.5) and the one-to-one levels of support the Initiative afforded. The latter was very important to caregivers and differed considerably from other more conventional service supports:

> *It’s having the time to sit with Dad; usually the carers (non-DSW care workers) are kind of coming and going. People don't't’ normally have the time to sit and talk or sit and play music, so it’s kind of different in the sense that they can provide that. Whereas the others [non-DSW care workers] are more hands-on with the activities of daily living. [Family caregiver 4]*

Improvements noted in the QOL of persons with dementia comprised better mood, higher level of confidence and energy levels. It is not surprising, therefore, that when asked to comment overall on their views about the supports provided under the DSWI all of the family caregivers stated in striking unison how satisfied they were with the programme:

> *Oh absolutely [satisfied], I mean I could have her coming everyday I’d be delighted. [Family caregiver 9]*

> *Very [satisfied], very, we were, yeah, genuinely. I would certainly recommend, it has been a really positive experience, particularly in the current climate where there aren’t a lot of resources out there, ehm, for the patient or for the carers, yeah. [Family caregiver 4]*

Their comments were reiterated by some people with dementia who also expressed overall satisfaction with the programme:

> *Interviewer: So if asked overall how satisfied with it what would you say? – Person with dementia: It’d be a big ten. - Interviewer: Ten? Ten out of ten? – Person with dementia: Yes - Interviewer: A hundred percent? – Person with dementia: Yes […] it would, it would, it would. A big ten … it was. [Person with dementia 8]*

> *Very good I mean, it’s just very good, you know, there was no doubt about that. [Person with dementia 7]*

> *Oh, I would [be satisfied with it] yeah. Oh God I would yeah. I think it is a great project. [Person with dementia 2]*

In one unusual case the DSWI had contributed to quality of life by reducing financial concerns. Having the DSW coming to the house for two hours per week helped the family to cut back a little on expenses for private home respite. In her own words:

> *It has in the sense that we're, it's cutting back on private health for those hours in the week. That's basically [...] financially it is [some savings], yeah, yes, it's small but... [Family caregiver 12]*

4.16 Sources of Concern

4.16.1 Stopping a Valuable Service

Despite the DSWI being very positively evaluated by most, a small minority were critical of certain aspects of it. A key criticism centered on the ten weeks duration of the Initative. Whilst caregivers seemed concerned about the logistics of this start-stop approach to the DSWI, it being a pilot project and the gap in support its discontinuation would mean, people with dementia seemed more concerned about the prospects of their being separated from a confidante and someone whose company they clearly enjoyed:

> *I have thought about that already and I have said 'Yeah, right at the end of the ten weeks then what happens?' and it is a pilot project and will it fold? Will it be continued? And where does that leave Mam at the end of the ten weeks? [Family caregiver 3]*

> *That it's only a pilot study I gather and I thought "Oh my God if this is taken away", like, that that would be the awful thing because it's a huge, there's a huge gap and ... they're getting to know the needs. [Family caregiver 7]*

> *Person with dementia: She was brilliant and-and when she was going away, oh, what would I find this sad. – Interviewer: Were you? When it ended, yeah? – Person with dementia: Yeah, yeah-yeah, yeah. - Interviewer: You were sad, yeah. – Person with dementia: Yeah. [Person with dementia 8]*

> *Interviewer: … and when it came to an end after the ten weeks can you tell me how you felt then? – Person with dementia: Oh, I'm, I miss it. [Person with dementia 5]*

> *Person with dementia: And I really miss that girl that came. – Interviewer: Do you? Do you? – Person with dementia: I do [with emphasis], you know, I-I haven't really got back into it, the stuff I was doing since she left. [Person with dementia 10]*

4.16.2 Uncertainties and Fear of the Future

A common theme running through the interview data was uncertainty and for many a fear of the future. This was manifest not just in a fear of the DSWI folding: "What is the future for the scheme?" (Family caregiver 5) but also about the illness trajectory itself and how the illness would ultimately affect their relative.

Some people with dementia also talked about the difficulties they would encounter attempting to in the future continue their leisure interests (painting and gardening) in the absence of their support worker who clearly inspired and motivated them. For example, when asked how she felt when the DSWI came to an end, one woman replied:

> *Oh, I hated it […] I did, I really hated it, you know, I miss her especially now because I have this stuff in there and I put it in a box and […] I-I just can't, I did a little bit of painting but I can't get down to do it like I did with her, you know, yeah. [Person with dementia 10]*

> *Hem, well, it's difficult [on my own) with the garden, you know, you can't… sort of go out [on my own] and wield a spade, can you? You have to build up to it. [Person with dementia 5]*

4.16.3 Other Concerns

One family caregiver complained that she had not been informed that the Initative would finish after ten weeks. Another family caregiver, who always left the house when the DSW visited, commented that she would have liked more feedback after the visit from the DSW. Another caregiver claimed he was not given any further information about other support services, which might have helped. As shown in the data, many caregivers were stressed and it may therefore be possible they may not have retained information and advice given to them by the DSWI staff. This is not surprising, since people under stress are less likely to retain information (Ellis & Hertel, 2014). However, another couple who did not appear at all stressed and who had a low ZBI were adamant that despite asking they were given little information about the Genio Dementia Project or the 5 Steps project and had to research this themselves on the Internet. They were particularly interested in the ways in which the 5 Steps Project might help the two of them to continue doing the things that they like doing (both together and separately), which has been shown to be an important component of new models of respite services (Armstrong & Shevellar, 2006).

Other complaints centered on the person-centered nature of the Initiative. One woman with dementia felt unhappy and claimed that the home-based therapeutic activities offered were for her not particularly enjoyable and she would have much preferred to use the time to go on shopping trips. Her husband also claimed that the exercises performed in the fitness class were too demanding for her as she had severe mobility problems. Another person with dementia claimed she was excluded from decision-making about who her support worker would be and over the actual day and times the DSWI support would be offered. She argued that visiting times clashed with those of other home-helps coming to her house and put this woman with dementia under pressure. Finally, one woman would have liked if the support worker had a car and a drivers' license to bring her out and about.

5. CONCLUSIONS

The study's findings clearly show, that for this sample of people from South Tipperary, the DSW Initiative was an effective model of respite care. The data show convincingly that the majority of people with dementia who had good insight and their family members expressed high levels of satisfaction with this new initiative. A diverse range of activities were provided during respite hours and the flexibility of the programme, along with the skills of the staff, its therapeutic ethos and the extent to which the intervention was truly person-centered with a focus on social inclusion (sometimes linking families into other service supports) were beneficial aspects commented upon by many. The personal and professional qualities of DSWs seemed to matter a lot to the participants and arguably was a most important factor contributing to their positive evaluation of the initiative.

The rich narrative conveyed a sense that support staff (DSWs) employed through the DSWI really grasped the complex challenges confronting these people because of their dementia, inspired confidence in them and allowed them to make decisions on their own. Staff members were described as being highly professional and skilled in communicating, in respecting peoples' individuality and values and in enhancing their well-being. The personal and professional qualities of the staff seemed to matter a lot to people with dementia and were a critical factor in their positive evaluation.

To summarise, the Initiative, which was concerned with how the time of the person with dementia would be spent during service provision, reflects a shift away from the more traditional passive type of respite service. The qualitative data provide compelling evidence of how the initiative could yield positive outcomes (albeit at times quite different) for both the person with dementia and his/her family member. However, at this point there was limited evidence emerging from the data that the DSWI might help family members continue to provide home care for longer. This may be due to the fact that most people in the research had a mild to moderate dementia and consequently it would have been premature for many families to consider long-term residential care at this stage.

One key limitation of this evaluation is that we were unable to capture data prior to the DSWI being introduced, since by the time families were approached for study participation, most had already commenced the new service. Ideally, it would have been useful to collect data on quality of life and caregiver burden both prior to and immediately after the respite service was introduced in order to have a more in-depth look at these peoples' lives. Obviously however scales like the ZBI and the QOL-AD have been devised for larger sample sizes and the numbers in this evaluation were very small so even if pre-test and post-test data were collected, the findings would need to be cautiously interpreted.

Another limitation of this evaluation is that the sample was biased towards people with dementia who had family members living at home alongside them. Only four of the 12 people with dementia receiving the DSWI, lived alone and indeed one of these four people had his son living next door. It would be very helpful to ascertain how this new model of service delivery as piloted here might help to sustain home care for people who have no co-resident caregiver and who may be at greater risk of an early admission into long-stay residential care. Likewise the sample had a disproportionate number of female caregivers (10 out of 12) probably reflecting the reality that caregiving is a gendered issue. It would have been useful however to have had more male caregivers to ascertain how their experiences may differ. Certainly the two male caregivers in this study had the two lowest caregiver burden scores.

Finally, this study failed to address the cost-effectiveness of the DSWI and furthermore, it is difficult to deduce from this study what the more long term and lasting benefits of an Initiative of this kind can yield. Whilst attempts were made to explore this issue in the research, the effort in the study was more to determine the short term (a day or up to a week later) enduring effect of the respite, in terms of mood, motivation and wellbeing, as opposed to the more long term enduring effects such as how people might feel months later. Clearly to capture information of this kind, a more longitudinal design would be required.

It would however be reasonable to deduce that the impact an initiative of this kind has on a local community must be far reaching. The project in itself reflects a community response to dementia and the data showed the way in which the interventions provided addressed complex issues such as social exclusion and made people feel less isolated and more supported within their local community. Several were linked into agencies such as Carer Support Groups, Alzheimer Cafes, and Physical Fitness Programmes where they were afforded opportunities to meet with others and helped to negotiate their way through a complicated service system. This in our view is an additional and probably more enduring benefit of a project of this kind.

The findings of this evaluation show that the DSWI was not a substitute for other more traditional forms of respite support such as day care or residential respite since more than half of the participants continued to avail of these other respite services. In addition, a small number of family caregivers who provided around-the-clock care would have considered using residential respite services if these were available. Whilst the DSWI provided additional support for some, it succeeded in offering others who were less inclined to attend a Day Dare Centre a welcome alternative and an opportunity to participate in meaningful and therapeutic activities and to engage with other people outside of the family. However, not everyone found the intensive tailored one-to-one interaction easy. For this group, it seems that there may be a need for community based/collective activities and recreations other than Day Care Centres to be developed and made available. This would require further exploration with people with dementia and their family caregivers.

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Genio is supported by the Atlantic Philanthropies in collaboration with the Department of Health and the Health Service Executive. We work in partnership with all stakeholders to re-configure resources to reform services in order that they reflect national policy and international best practice.

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