An Evaluation Report on Flexible Respite Options of the Living Well with Dementia Project in Stillorgan and Blackrock

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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.

We would also like to acknowledge the support and expertise of the Genio International Research Advisory Committee chaired by Dr. Ruth Barrington. This includes Gail Birkbeck, Sarah Craig, Dr. Bob Illback, Dr. Fiona Keogh, Prof. Jerome Bickenbach, Prof. Philip McCallion, Dr. David McDaid and Prof. Gerard Quinn.

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; Stillorgan and Blackrock in Dublin. Based on discussions with people with dementia and family carers, a number of community-based supports were developed which were designed to meet the needs of both the person and carer and this report presents an evaluation of one of these, an activity/exercise group. The evaluation was carried out in the very early stages of the development of these community supports, involving nine people with dementia, eight family carers and one formal carer. 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 individual's experience of living with dementia, the caregiving role and the impact of this initiative on both.

The main findings were that these interventions addressed a variety of complex needs for both the person and the carer, often in different ways. 'Mainstream' recreational and social activities coupled with an innovative transport solution, produced a range of positive outcomes for the person and the carers. The family carers particularly welcomed the structured and integrated aspect of the programme, combining physical exercise, psycho-social stimulation, carer support groups, transport provision and key contact workers.

As mentioned, the report captures peoples' experience of this initiative at a very early point in time and when respite supports were at a very early stage of development in this site. Suggestions for changes to the programme have already been incorporated and a further range of respite supports and services have now been put in place and are being continuously refined in response to the unique needs of each person and family. An evaluation of this more fully developed 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 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

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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 organisation 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 disabilities and mental health difficulties. 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, Living Well with Dementia (LWwD) Stillorgan-Blackrock was one of four sites selected for funding through the Genio Dementia Programme. As part of its programme, LWwD Stillorgan-Blackrock was established to demonstrate how new models of community –based respite care 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 typically 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.

1.1 Aims and Objectives

The broad objectives of this initiative have already been described in the last section. These were later refined by O'Shea & Murphy, (2014), to ensure that the new service initiative would:

- Mobilise the local community to raise awareness and reignite old or develop new recreational and social activities for the person with dementia, providing innovative transport solutions to enable the person with dementia travel to such activities.
- Establish a dementia hub at the centre of the community.
- Provide specialised dementia care training for carers, volunteers, health service professionals and the broader community.
- Provide a range of flexible respite supports informed by the desires of persons with dementia and their family members.
- Facilitate the discharge of persons with dementia from residential care to community care and conversely delay or avoid the use of long term residential care.
- Pilot a range of assistive technologies.

LWwD Stillorgan-Blackrock, located in the Southside Partnership offices, is led by a HSE Manager of Services for Older people, a Nurse practitioner with a wealth of experience in ageing and dementia and with long established collegial relationships with staff from the local primary care team. The wider consortium includes a GP, members of the primary care teams, a carer and input from people with dementia, the Southside Partnership, Community Employment, TUS- Community Work Placement scheme, a community Garda and NGOs, including the Alzheimer Society of Ireland (ASI), as well as representatives from Medicine for the Elderly and Old Age Psychiatry departments at St Vincent's Hospital.

Based on discussions with persons with dementia and their family caregivers, two community-based respite supports were developed in the Stillorgan/Blackrock area. The two respite supports trialled were an activity/exercise group led by trained physical therapists from a private not-for-profit organisation and a Musical Memory Choir[1] operating in partnership with Dun Laoghaire-Rathdown County Council Arts and Health Partnership. This report presents findings based on an evaluation of the first intervention and provides insights from caregivers and persons with dementia about their experiences of using this intervention. LWwD Stillorgan-Blackrock also arranged intensive in-home respite support for selected families living in the Stillorgan and Blackrock areas who were providing round-the-clock care for their relatives, who had advanced dementia and were at risk of being placed in residential long-stay care. The caregivers in these families were under immense strain and these respite supports were put in place in an attempt to help these families keep their relatives at home, according to their wishes and those of their relatives. It should be noted that data collection for this evaluation took place some few weeks after the new service interventions were introduced – hence during the very early stages of this programme. The programme has developed over time and changes have been made in response to feedback from those participating.

2. METHODOLOGY

The approach adopted for this evaluation was primarily qualitative. As the research focused on a small number of families (N=9) in receipt of a new model of respite supports, a qualitative approach, using an exploratory design, was deemed most appropriate for the task at hand. This also ensured that the experiences 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

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[1] Most people referred to this activity as singing for the brain. This activity is not evaluated in this report as only three people attended it at the time the evaluation took place.

qualitative approach was complemented with some quantitative data collected on quality of life and caregiver strain.

2.1 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 respite supports. The purpose of these interviews was to evaluate the impact of the respite supports 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.

2.2 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. Permission was gained from Logsdon to use this tool. 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. 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 audio-recording the responses to the QoL-AD meant that when some of these questions prompted participants to reflect on issues relating to the respite supports that had not already been discussed in interview, this information was 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

Likert 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 the carer's 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 1 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 nine of the ten participating family caregivers (i.e. family caregivers in 9 cases).

2.3 Interview Schedule

Following an extensive literature review on the topic of dementia and respite care interventions and discussions with staff to establish the respite supports being developed and on offer, an interview schedule was designed which addressed the broad topics of dementia care and service supports. The schedule had a particular emphasis on the respite supports offered by LWwD Stillorgan-Blackrock 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 staff involved in delivering these services and (iii) the person with dementia's and family caregivers' perspectives about the supports, along with their views on the discontinuation of this service, where relevant. 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 long term residential 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.

2.4 Profile of participants

The participants consisted of nine people with dementia, four men and five women, eight family caregivers and one formal (i.e. paid) carer[2]. Five of the family caregivers were spouses (two husbands and three wives), two were sisters of the person with dementia and one was a daughter (who worked). Five of the nine interviews were conducted with family caregivers and people with dementia jointly. In addition one joint interview was conducted with a formal caregiver and a woman with dementia. Whilst no clinical rating scale for dementia was used to measure severity of dementia (McCulloch et al., 2013; Zaidi, Kat & de Jonghe, 2014), based on interviews undertaken, a broad range of dementia severity was represented, with six of these men and women showing signs of mild to moderate dementia and the other three showing signs and symptoms of more severe dementia.

Many of people with dementia participating in the study had other serious chronic health problems and sensory disabilities, which impacted on their quality of life and increased their need for support from family members and formal care supports. Arthritis was a common problem experienced by about one third; it resulted in significant pain and in one case caused serious mobility problems. In another case, the woman was awaiting a call for a hip replacement. One older man was quite deaf, had a pacemaker and was physically very disabled by virtue of contractures[3] in his hands. Another woman who had Vascular Dementia, hypertension, heart problems, fatigue and severe Osteoporosis appeared as disabled by her arthritis as by her cognitive impairment.

Several of the older family caregivers did not enjoy good health: “I got a new hip three years ago” [Family caregiver 6]. Some were on medication for their health and reported that they had their own hospital appointments to attend. One man caring for his wife explained that he had prostate cancer and two women caring for their husbands had muscular-skeletal problems, which limited their caring. One sibling who shared the

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[2] This person had a family caregiver but after much discussion with the primary family caregiver it was decided that it would be more valuable for one of the paid carers to participate in the interview, since she was the person who accompanied the woman with dementia to the exercise programme.

[3] Permanent shortening of the muscles.

caring role with her husband (who had had an aneurysm some years earlier) worried considerably about the effect caring was having on his health.

2.5 The organisation of LWwD Stillorgan-Blackrock

As stated earlier the overall responsibility for LWwD Stillorgan-Blackrock lay with the Project Lead (see page 4) who had strong support from all of the participants in the consortium which covered a range of health care professionals, voluntary groups, other non-health related statutory organisations and community groups. The project manager was employed by Southside Partnership and reported to the project lead daily. Community Employment (CE) and TUS (community work place initiative) staff were sourced through the Southside Partnership to provide administrative and community support services to the consortium (O'Shea & Murphy, 2014).

3. FINDINGS OF STILLORGAN/BLACKROCK RESPITE EVALUATION

3.1. Why was the programme of respite established?

As mentioned earlier, one of the aims of LWwD Stillorgan-Blackrock was to provide a range of flexible respite supports to a select number of families. It was informed by the desires of persons with dementia and their family members. It was also designed to mobilise the local community to raise awareness and reignite old or develop new recreational and social activities for the person with dementia, providing innovative transport solutions to enable the person with dementia travel to activities. The exercise programme commenced in February 2013 and was delivered by a private not-for-profit organisation that employed physical therapists specially trained in dementia care.

Referral sources were multiple and included local health service professionals including GPs, Old Age Psychiatry staff and public health nurses. Self-referral to the service was also acceptable. The exercise programme was always followed by a social gathering where participants could relax over a cup of tea and enjoy the company of the other participants and a team of volunteers including school children that supported and befriended these families. Most of the participants involved in this project were also being supported by more mainstream HSE and ASI dementia-specific services and several also employed and paid out of pocket for private in-home support.

The exercise programme offered 60 minutes of gentle exercise including arm, hand, leg, foot, neck, head and body movements to people with dementia and their caregivers if they wished to join in. The period of time that participants in this research evaluation (N=9) had been attending the programme varied. However, at the time of interviewing several had only recently started the programme and in one case the family following much consideration had decided to withdraw. In this case, the decision was based on the observation that the programme was not providing any real benefits to the woman with advanced dementia. Her husband, the primary caregiver, said that outcomes may have been better if the programme had been offered earlier when the dementia was not nearly as severe.

Most of those who registered for the physical exercise programme were not physically assessed in advance and preliminary findings would suggest that given this was a group rather than individual activity, some difficulties arose in tailoring the programme to individual needs. For instance, in some cases the exercises were considered too passive, in others too aggressive or difficult. One man with dementia was profoundly deaf and would have had difficulties following instructions. Another man was blind in one eye and likewise may have had difficulties following gestures and instructions. Another person with dementia, whilst enjoying the social aspects of the programme, found the exercises rather childish.

A particularly appealing aspect of the programme was the fact that it offered families an integrated type of service where project staff effectively coordinated the service on behalf of their client group. This meant that most families were exempt from having to worry about transport to and from the service (taxies were arranged) and the gentle reminders by way of weekly phone calls to prompt service use, were also regarded as an appealing aspect of the programme and greatly appreciated – "X always rings on a Tuesday morning to see if we are coming" [Family caregiver 6].

Another very appealing aspect of the service was the opportunity it afforded for socialising after the activity programme took place. Indeed for one person, who felt unable to keep up with the pace of the programme, this was the most appealing aspect. In another case, the man's wife would have liked this aspect of the programme to continue for longer. As mentioned, each week tea and coffee was served immediately following the programme and a staff of volunteers including local school children assisted. The value of this integrated package was well illustrated by several of the family caregivers:

> *"The staff are just exceptional ... they set up this business where they collect, bring and collect, now in (mentions her sister's name) that is just vital because I am not around all the time ... so if I wasn't here ... she wouldn't get to go ... and then there's the cup of tea." [Family caregiver 9]*
>
> *"You know every week they check you out, they warn you in advance, they do all these kind of stuff so that it probably seems kind of easy peasy and I think that's an amazing thing to get from an outsider." [Family caregiver 8]*

3.2 What unmet needs were intended to be addressed by the respite services?

Boredom, loneliness, the need for occupation, social engagement and physical exercise were some of the unmet needs of people with dementia being addressed by this programme. Although there is a convincing body of literature now demonstrating the value of physical exercise for older people in general (Sun, Norman & While, 2013; Williamson & Pahor, 2010) and for those with dementia (Forbes et al., 2008; Heyn, Abreu & Ottenbacher, 2004; Pitkaelae et al., 2013) both in terms of cognitive health (Bherer, Erickson & Liu-Ambrose, 2013; Tseng, Gau & Lou, 2011) physical health (Chou, Hwang & Wu, 2012; Littbrand, Stenvall & Rosendahl, 2011; Paterson & Warburton, 2010), and overall well-being, it was the opportunity the intervention afforded these people for social engagement and for remaining integrated into their local communities that was by far the most important and unique aspect of the programme and it was this aspect that was frequently commented upon by both people with dementia and their family caregivers.

Several people with dementia in the sample lived alone and had limited contacts with the outside world apart from service providers periodically calling to their homes. Indeed, some actually alluded to feelings of loneliness: "I'm the only one here most of the time but I don't like being without my other people so maybe they will turn up" [Person with dementia 5]. Family carers were quick to identify the benefits derived from this programme in terms of it combating loneliness. Many caregivers had real concerns about their relatives being socially isolated, their lacking psychosocial stimulation and their having nothing to keep them occupied at home. They talked about the value of the intervention in terms of its capacity for social engagement:

> *"The social aspect to the exercise programme which [people with dementia] need [is] very important […] people are chatting as the exercise goes on […] talking and laughing with each other throughout all this […] a certain uplifting of spirits […] physical, mental for the sheer enjoyment and social contact." [Family caregiver 10]*

> *"I think loneliness, a lack of social interaction, all that kind of thing kills people sometimes more than heart attacks and cancer. It's loneliness […] I'm sure she is lonely but [the programme] will definitely help her." [Family caregiver 9]*

> *Interviewer: "Right, okay, so does that make a difference for you then?" – Family caregiver: "Of course it does, of course it does. Because I actually think mostly the thing with you, X, was the isolation […] I think X has a very good sense of humour, you know, but […] if you're immobile it's very hard to be and it is, it is, I suppose it's just the chatting, talking to people and all of that." [Family caregiver 8]*

In a similar vein, several people with dementia when asked to comment about their experience of the programme talked about how it helped to enhance social connections:

> *"There's chat going on all the time and a chance afterwards to gather around with others attending and have tea and cake and socialise - a reward for your efforts, something which [I think is] extremely important." [Person with dementia 10]*

> *Interviewer: "… and do you like the social aspect to it because I believe there's tea and coffee and cake afterwards?" – Person with dementia: "Yeah ... well. – Interviewer: "and people will have a chance to sit around and talk?" – Person with dementia: "Yes, and to some people like you can relate … reasonably well, like, those are the people coming." [Person with dementia 8]*

> *Interviewer: "Do you enjoy mixing with the people there?" – Person with dementia: "Uh yeah […] we all know each other […] that's it. But if you like it or not, that's... that's it... yeah [laughs]."*

One woman with a more moderate to severe dementia referred quite positively to the exercise programme and referred to it as 'work' , as if 'no slacking' was allowed on the job and that participants were encouraged and to a certain extent expected to partake in the exercises rather than sit idly by. In her view it seems as if the exercise programme was all business:

> *"Once you're there you have to be sure that you're going to do, this is all work down there and then we can come home […] when we go down there then we have to do things […] because they keep coming in and we'll notice when it's time for us to go out and you'd see other people coming in and others going [laughs]." [Person with dementia 5]*

In another case, where the person with dementia had at one time been heavily medicated and had been hospitalised five times in recent years, her daughter, the primary family carer talked at length about the value of the exercise programme both in terms of her witnessing improvements in her mother's mobility along with its usefulness in helping to structure her mother's week ("otherwise she might not even know what day it was"). This weekly activity made her feel "normal" and gave her the motivation to get up and go:

> *"She loves the idea of leaving the house … She loves the idea of getting herself ready, having her shower, getting her clothes ready to actually go out. It keeps her focused to the day." [Family caregiver 9]*

In this same case the family carer could identify very definite physical improvement, especially in terms of her mother's mobility which she partly attributed to the programme:

> *"Now when I think she can do the round trip (meaning walking alone from her home to her daughter's) and when I see her coming in walking and she'd walk to the post office and she'd walk back over to me, stay with me for about a half an hour and then I'd say – I wouldn't even say "are you walking back?". She'd say 'I'm going back now' […] something must have been working because certainly like a year ago [she was not capable of doing this]." [Family caregiver 9]*

Like several others in the sample, this woman had a mild dementia but it seems that her physical health, including her Osteoporosis resulting in severe pain, affected her quality of life probably more profoundly than her cognitive impairment. Indeed sadly in this case, as a result of severe pain this woman had missed the exercise programme in the week prior to interview:

> *"She didn't go last week because she was afraid to go in case she hurt herself. So I was wondering maybe if the group would instead of doing exercise for everybody may be just a social interaction for some people." [Family caregiver 9]*

In discussions about the value of the exercise programme, most carers mentioned the way in which exercise was salient to their relatives' former interests and life stories. One woman, for example, had been an avid hill walker but now could no longer do this and hence the programme gave her an opportunity to resume a quasi-fitness programme. Another woman was used to cycling. The wife of a former athlete commented:

> *"He always liked exercise, always […] he wouldn't object to exercises, he likes exercises. When I heard about it straight away I said 'oh, yes, [he] would like that'." [Family caregiver 7]*

> *Family caregiver: "You used to walk miles." – Person with dementia: "Yeah [laughs]."– Family caregiver: "Miles and miles and miles [...] yeah, I know you would have done a lot of walking." [Family caregiver 8]*

3.3 How did the respite service attempt to meet these needs?

Based in the community, the exercise programme attempted to tackle the stigma of dementia by introducing normal everyday activities that anyone could enjoy and which were not exclusively associated with being old, having a dementia and being dependent. Indeed, the fact that this programme was not exclusively designed for people with dementia and other local people without dementia also attended was particularly novel. This normality aspect gave the programme added value and was commented upon by several. Programme participation also gave some of these people with dementia a sense of independence and empowered them to take more control over their lives:

> *"She is going somewhere, exactly. and I think it also gives her, she like talking about it as if ... you know the independence, like 'I go to my group and I'm going to my singing' ... it makes her feel like ... what normal people do ... so it makes her feel a little important and independent and it gives her a reason to get dressed and to spruce herself up a little bit more in the mornings ... and oh it's empowering ... I really believe that...." [Family caregiver 9]*

As mentioned in the introduction, many of these people were availing of other private, voluntary and statutory respite supports through local and more conventional services. LWwD Stillorgan-Blackrock, however, differed from the more traditional models of respite insofar as it was flexible, integrated, personalised (families received regular phone calls and updates on events happening in the community) free of charge and of a short duration.

Indeed several of the participants commented on the short duration of the programme (60 minutes exercise, 30 minutes for socialising), a feature considered by many as very attractive compared with the more long term commitment required by other more conventional respite services:

> *"I think it's (exercise programme) probably long enough, eh, because, ehm, before this my Mum was going to the day care centre in X […] I'd drop her up there around […] 10 o'clock on a Monday and I'd collect her about two or half two. I found it was too long for her and she was too tired and it took a lot out of her and she, like, it took her all day Tuesday to recover […] it's too long for her. I think an hour and a half to two hours is maximum, really, for that age group because my Mum has heart problems and she would find her stamina, you know, she'll find she'd feel, eh, she suffers from hypertension, she gets tired easily. So an hour and a half is perfect." [Family caregiver 9]*

> *"People don't want things like for hours on end. They just want kind of a maybe a two hour thing -is enough and that's enough an activity for a day, and you don't have to have it every day, you know, and maybe it is nearly impossible because there's so many people coming in and out but in one sense you're, you know, they're not coming in for five hours on the trot or whatever." [Family caregiver 8]*

Many family carers were burdened albeit not that severely (see page 26 for a more detailed overview of caregiver burden) by the demands of caregiving. Several of the non-spouse carers, three daughters and two sisters (none of whom lived with relatives) had other competing demands on their time including own work and other parenting duties. They often worried about their relatives particularly at night and at weekends when more formal traditional support services were not available.

In keeping with the literature (Dewing, 2008; Nolan et al., 2002; Twigg & Atkin, 1994), the data show how caring affected many other family members (besides the primary caregiver) who were often drawn into caring tasks such as monitoring drug compliance, home maintenance, driving the person with dementia to various appointments, dealing with solicitors, checking on the person's use and mis-management of money and ensuring the person would remain safe. For the majority, the respite programme afforded them and indeed other family members a much-needed break from the daily demands of caring for their relative with dementia. Whilst caregivers had the option to accompany their relatives to the exercises, several took the opportunity to take time out.

> *"I go for a walk [if] it's a nice day, you know." [Family caregiver 6]*

> *"It means a lot, yes ... yes, just some relief from on-going activity with him or repetition and just watching." [Family caregiver 7]*

3.4 What service model was adopted and how did this differ from previous service models of respite?

This respite intervention differed considerably from the more conventional models in a number of ways. Most notably, respite has been traditionally considered a service that 'physically or socially separates one party out for the benefit of the other' (Armstrong & Shevellar, 2006). In contrast, the exercise programme offered here allowed carers accompany their relatives and encourages their active participation.

Traditionally, in Ireland, approaches to respite care for people with dementia have been underpinned by the biomedical model. This model has in the past tended to disempower people, relegating them to the status of passive service recipients and distancing them from their community. People are "brought to" day centres or "put into" residential respite care in settings where they often have to fit into organisational requirements, rules and routines. The latter is far from ideal for a person with dementia who is often prone to anxiety and panic and needs to be in a familiar environment. In contrast this physical exercise programme was based in the community, in venues that people with dementia and their family caregivers seemed familiar with and which were used by other community groups. One man with young onset dementia for example was able to walk back and forth alone to the programme.

In sharp contrast, the biomedical model has tended to focus on the disease rather than on the person and on that person's lost ability and deficits rather than on his/her retained ability and strengths. Services, which have been spawned by this biomedical approach, tend to result in dementia remaining hidden in society and not owned by the community. Family caregivers are marginalised; the experts are the health service professionals and those responsible for medical scientific research (Kitwood, 1997). The model is not generally inclusive of individual or family preferences and tends to cater for groups rather than individuals.

The project respite programme in contrast is underpinned by a social/disability model of dementia care. This model gives voice to the individual, encourages him/her to be an active participant in decision-making and provide opportunities for relationship building and social inclusion within given communities. The model is a lot more flexible compared with conventional models. It empowers the individual and the family caregiver both of whom are viewed as experts. In other words people do not fit into what service providers consider as appropriate but rather they themselves help to shape up the type of service they ultimately receive. One of the advantages of the physical exercise programme was that it has broadened the types of activities on offer to people with dementia and their family caregivers, as previously there was very little else on offer other than traditional day care or residential respite. The regular but short duration of the programme also set it apart from existing more traditional support.

3.5 How effective was the programme of respite service in meeting the needs of people with dementia?

Whilst participants with dementia were not particularly forthcoming themselves in describing benefits derived from the actual physical exercise programme itself and tended to rate it only equivocally; One woman caring for her brother with dementia reported that he often asked "Do I have to go again"? Another man with a more severe dementia when asked if he liked it replied: "Oh yes, I'd be happy enough but it won't, it won't interfere with me so or encourage me either" [Person with dementia 7]. Another said "I get bored" [Person with dementia 6]. In contrast, and in the main, family members interviewed evaluated LWwD Stillorgan-Blackrock very positively and most could readily identify some improvements either in their relatives' physical health, mood, mobility and overall quality of life, some of which they ascribed to the intervention.

> *"It's made a big difference, it has, and even if he only gets some sort of […] exercise and stuff out of it it's, it's good for him. It has to be, it has to be, and it'll probably*

> *keep him more mobile, true you see. He is pretty mobile as it is but, you see, it helps too that when if you, if [my husband] brings him back and [he] wants something in the shop, he's going to go down and get it like he always did." [Family caregiver 4]*

> *"Her mood has improved big time, you would have been very anxious in, in earlier in the year, very anxious." [Family caregiver 8]*

> *"It's very, very good, you know, each and every part we are doing is very good for something, you know, it's okay for [her] and then they'll play, playing with-with a ball, you know, it helps [them], you know, [with] the hands, everything." [Care Worker 5]*

> *"It will make her more healthy mentally and anything that makes you more healthy, healthy, healthy mentally helps you physically [...] the fact that she has this [...] it'll make her, give her a better quality of life, yeah." [Family caregiver 9]*

> *Interviewer: "How is her life as a whole at the moment?" – Family caregiver: "I think certainly a hundred percent better than it was, two hundred, five hundred percent better than it was [...]". – Interviewer: "A lot better than it would have been before she was involved in these programmes?" - Family caregiver: "A lot better, yes, a lot better, yes, yeah-yeah, yeah." [Family caregiver 8]*

Despite this positive evaluation, there were five cases where it was reported that the exercises were not tailored to the individual's fitness levels. In three cases, exercises were considered to be much too hard and interestingly, in the other two cases, it was argued that the exercise were not sufficiently challenging. The dilemma involved in attempting to develop a programme of exercise for such a heterogeneous group of people was well articulated by one of the interviewees when she said:

> *"I think it's very hard for them to individualise a programme when all the people that are attending it are at different stages, you know, and some of them are improving by the day and some of them are deteriorating, you know." [Family caregiver 9]*

3.6 How effective was the programme of respite in meeting the needs of family caregivers

A novel and highly rated aspect of LWwD Stillorgan-Blackrock was a Carer Support Group which met intermittently. These meetings involved a guest speaker usually a health service professional who gave a themed talk on a topic of direct relevance to dementia and caregiving and where family carers could meet, mingle and exchange experiences. All five family caregivers who attended this Support Group had educational and information needs, which they claimed, were well addressed by the programme:

> "*They make available information that otherwise I wouldn't have the time to access. I'm just too busy." [Family caregiver 10]*

> *"I went to one [Carer Support Group] recently … which was very good. It was a talk by, eh, by an occupational therapist, and just the practical aspects of her home, [a] couple of good tips actually, like, touch-lights at the edge of her bed, ehm, the emergency response […] I'm going to start, eh, trying to get that one installed downstairs […] and then… they had a talk about psychology, like, say for example if your mother, eh, the behaviours that they have as a child are exaggerated when they get older. If they don't like bright lights when they are younger then they hate them now. Something like that, and I thought that was helpful, eh, the, yeah, the personality doesn't change it just exaggerates. That was a very helpful, yeah, pieces of information […] it gets you thinking." [Family caregiver 9]*

Apart from Carer Support groups addressing carers' practical and information needs, the overall programme also served the purpose of helping carers cope with the physical and psychological strain of caregiving.

> *"It just takes the pressure off you because you feel, well, on Tuesday she'll have her home help coming in the morning and I work Tuesday, Wednesday, Thursday so I mean on a Tuesday I feel 'well, okay, she has that, then the afternoon she has this [the exercise group]." [Family caregiver 9]*

> *"I don't feel, eh, you know I'd be worrying all the time, now I know I can make a phone call or whatever it is." [Family caregiver 8]*

> *"It's made a big difference [to us and the way we are coping]." [Family caregiver 4]*

Others talked about the improvements they noted in their own care-giving skills, including their being more highly incentivised as a result of more positive interaction with LWwD Stillorgan-Blackrock staff.

> *"I think they've been helpful because, you know, where were we going to go without it? It was another two days of [my husband] up and down and sort of flailing around not knowing what we were doing whereas this has put some kind of a structure on what we're trying to do and it's helped us to step by step, you know, that what you should do next and what's important." [Family caregiver 4]*

Some talked about the benefits of the programme in linking them up with other carers:

> *"It's also good because well I find it good because I meet other people and can find out other things are going on." [Family caregiver 6]*

Most family caregivers (N=7) stated that they felt overall highly satisfied with the programme.

> *"It exceeded [our] expectations [...] to use a cliché, It has actually delivered what is says on the tin." [Family caregiver 10]*

> *"Oh, I would say excellent, yes, excellent, yes." [Family caregiver 7]*

> *"I enjoy it, it's very good." [Care Worker 5]*

> *"I think it's good. It's as good as people are able for it, you know. It's as good as the people are able to do and it's interactive." [Family caregiver 6]*

3.7 According to the client did respite care in any way help to reduce the need for hospital care?

In answering this question, one must give due consideration to the main reasons for admission of people with dementia to acute care. In addition, as caregiver burden including burnout and carers' own physical and mental health problems can lead to decisions to admit people with dementia into long term care (Cahill, O'Shea & Pierce, 2012), due consideration also needs to be given to the health status of the caregivers in this sample.

Regarding the sample of people with dementia, and as stated earlier, most of the participants in LWwD Stillorgan-Blackrock had a mild to moderate dementia and based on the interview data, most did not exhibit the type of challenging behaviours (sleep disturbance, incontinence, aggression, hallucinations, paranoia and delusions, and restlessness) which might otherwise threaten the sustainability of home care. Nor were these people prone to falls or accidents at home, incidents which might also have resulted in their need for hospital admission. Indeed, it was probably the physical health problems experienced by these same men and women (see page 8) as opposed to the dementia that might have placed them at greater risk of admission to acute care.

Regarding the family caregivers, as mentioned, most were receiving other support services outside of LWwD Stillorgan-Blackrock. Whilst some were moderately or mildly stressed (see page 26), most expressed a fervent desire to continue caring for as long as it was feasible. Several did not enjoy good health and had chronic health problems such as arthritis which more than likely would have been aggravated by caring. Indeed, based on the literature (Argimon et al., 2005; Mittelman et al., 2006), it is possible that some of the health problems experienced by them might ultimately lead to the breakdown of home care arrangements.

3.8 According to clients did respite care in any way help to reduce the need for residential long stay care?

It was clear from the interviews that staying in their own home was hugely important to family caregivers and the person with dementia. Whilst virtually all of these family caregivers expressed their concerns/fears for the future, because of their relatives' dementia, and whilst at least one family caregiver would have welcomed more family involvement, when specifically asked the questions whether they thought they might have to relinquish home care soon, most were unequivocal that this was very unlikely. A fairly typical response to this question asked about the sustainability of home care was reflected in the words of a woman caring for her brother who said:

> *"I think we've kind of made the decision that hopefully we can keep him at home as long as possible and then if necessary it'll have to be a nursing home." [Family caregiver 4]*

> *"….maybe down the line." [Family caregiver 6]*

Indeed a few of the caregivers explicitly referred to the capacity respite had to enable them to continue providing home care for longer. In their words;

> *"I definitely think, eh, it's a positive because it will [help her stay at home for longer]." [Family caregiver 9]*

> *"Participation by [my wife] in the exercise programme allows [me], her primary carer, [to get a break], [it is] crucial for [me] to get a break from caring 24/7 […] very, very important […] all of the health professionals that [we] had spoken to emphasised the importance of carers getting a little bit of respite here and there [in order to be able continue caring for our relatives]." [Family caregiver 10]*

They were however two exceptions. One was the man with a life-threatening illness, who was caring for his wife with dementia and who seemed conscious of his own mortality. On several occasions during the course of the interview, he referred to his own health. This same man availed of both private and HSE home carers five days a week including services from the ASI. When asked about his future capacity to continue to provide home care he said:

> *"Well, I've done nothing [about organising long term care] because at the moment we are going on the basis of using our own resources to provide for the assistance we require in the home … I'm not doing the rounds of nursing homes … the next stage of looking after X, if my condition deteriorated … at that point and then I might look at it from the point of view of what am I to do." [Family caregiver 3]*

The other person was an octogenarian spouse caring for her husband who found caring very stressful (she had the second highest ZBI score of 43), despite the fact that this family also availed of several other service supports including in home carers[4] and day care (three full days weekly);

> *"Having said that with all that [support] it seems to be quite a lot of help, I still find it stressing and straining." [Family caregiver 7]*

The biggest difficulty this woman was experiencing when interviewed was dealing with her husband's food obsession. This family had once used residential respite care and had a very bad experience when her husband had got out and been missing for some time. Stressing the fact that her husband "likes to be at home", this same older woman appeared to be very determined to continue to care ("for as long as I can") yet remained realistic that this might not be that feasible:

> *"Sometimes I think you know, I will be able [to continue to care] and other days, then – I won't be able to." [Family caregiver 7]*

3.9 To what extent did the programme of respite services overcome limitations identified in existing services

The limitations of other models of respite care have already been discussed (see pages 16-18). These include the longer time commitment required by the more traditional models of respite (half/full day respite or full week residential respite). However, the options available for families in the Stillorgan and Blackrock areas who were thinking

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[4] LWwD Stillorgan-Blackrock was centrally involved in helping to arrange in-home support for this family caregiver but she was not aware of their involvement in this. This was not an exceptional case, for example, it was not apparent to one family for whom intensive respite support was put in place that LWwD Stillorgan-Blackrock was responsible for this.

about availing of residential respite services as opposed to day respite were still limited. In addition, the limitations associated with these existing residential respite services have yet to be addressed. For example, the residential respite services available through the ASI programme in Dublin do not facilitate families to use overnight respite. Rather if they avail of the service they must use it for a minimum period of time.

Another limitation of existing respite services is the type of case management role family members had to play whereas with LWwD Stillorgan-Blackrock a packaged service was sometimes available and supports were geared towards involving people with dementia and their families in social activities. In contrast to respite services underpinned by a more generic approach, which are institutional and tend to separate family caregivers from their relatives (day respite, residential respite), LWwD Stillorgan-Blackrock was designed to promote a philosophy of 'continuing normality' by offering activities that are easily accessible, open to all and not restricted to those with a dementia, and by enabling the person with dementia to continue living in his/her long-standing local community (see page 12).

4. CAREGIVER BURDEN

As mentioned the Zarit Caregiver Burden Inventory (ZBI) was administered to the majority of family caregivers to collect data on the level of social, emotional, psychological, financial and physical strain these carers experienced. Analysis revealed (see Table 1) that the mean score on the scale was 29 (range = 12-57). Using Zarit's scoring typology,[5] data show that about two thirds of these participants had ZBI scores reflecting only a mild to moderate level of strain. Aggregate scores for another one quarter of the sample suggested they experienced little or no burden.

Interestingly, the carer with the lowest ZBI was a woman who had very good family support and lots of hobbies and interests- "I have a walk and I play bridge and I do a lot of things" [Family caregiver 6]. In contrast the carer with the highest ZBI at 57 was a relatively young woman who worked full-time and looked after her husband who had

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[5] Little to no burden= 0-20, mild to moderate burden = 21-40, moderate to severe burden= 41-60 and severe burden =61-68.

early onset dementia. This lady was concerned about how her husband's illness was impacting on other teenage family members. Like others during the interview she repeatedly stressed the importance of the specialist non-threatening approach to respite available through the programme – "[it's] somewhere for him to go to particularly being safe with people who understand his condition and are for him" [Family caregiver 11]. She made the point that keeping him occupied in a meaningful and regular way posed a big challenge for her. Referring to the exercise programme she said- "somewhere to go it probably gives focus to the day; I'm not his focus…" [Family caregiver 11].

In sharp contrast to this relatively young wife caregiver who was juggling multiple roles, the carer with the second-highest ZBI score at 43 was an octogenarian who was unsure whether or not she would be able to continue caring for much longer. This woman experienced a lot of pain due to her arthritis and found the night time care of her husband particularly stressful. She believed that physically and psychologically the exercise programme made no real difference to her husband who had severe dementia but like others she continued to emphasise the value of the social aspect of the programme – "he likes very much the tea and cakes afterwards" [Family caregiver 7]. Like family caregiver 11 who cared for her husband with early-onset dementia, this lady also felt challenged by providing her relative with meaningful activities as in her own words – "he hasn't much to pass his time other than television and he loses interest in that…" [Family caregiver 7].

Preliminary analysis of data also suggests that those with higher ZBI scores had more requirements for respite care. Although as mentioned earlier the majority of carers had real concerns about the future and felt their relatives were very dependent on them, most were neither embarrassed about their relatives' behaviour nor did they wish to leave their relatives' care to some other third party.

Table 1: Results on Caregiver Burden based on Zarit's Scale N= 8

Question	Never/ Rarely	Some- times	Quite frequently /Nearly always
1: Do you feel that your relative asks for more help than he/she needs?	7	0	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	1
3: Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?	1	3	4
4: Do you feel embarrassed over your relative's behaviour?	5	3	0
5: Do you feel angry when you are around your relative?	6	2	0
6: Do you feel that your relative currently affects your relationships with other family members or friends in a negative way?	3	3	2
7: Are you afraid what the future holds for your relative?	0	4	4
8: Do you feel your relative is dependent on you?	0	3	5
9: Do you feel strained when you are around your relative?	3	3	2
10: Do you feel your health has suffered because of your involvement with your relative?	3	3	2
11: Do you feel that you don't have as much privacy as you would like because of your relative?	7	0	1
12: Do you feel that your social life has suffered because you are caring for your relative?	3	3	2
13: Do you feel uncomfortable about having friends over because of your relative?	6	1	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?	5	0	3
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?	8	0	0
16: Do you feel that you will be unable to care of your relative much longer?	5	2	1
17: Do you feel you have lost control of your life since your relative's illness?	5	3	0
18: Do you wish you could leave the care of your relative to someone else?	6	1	1
19: Do you feel uncertain about what to do about your relative?	5	3	0
20: Do you feel you should be doing more for your relative?	6	2	0
21: Do you feel you could do a better job in caring for your relative?	5	3	0
22: Overall, how burdened do you feel in caring for your relative?	2	4	2
Mean Score = 29 (Range 12 – 57)			

5. QUALITY OF LIFE

The data collected on quality of life using the QoL-AD is limited due to the fact that two people with dementia were unable to complete the scale, another person's dementia was so severe she could not participate in the interview and in one case the proxy was a formal caregiver as opposed to a family carer. In another case the interview was not taped and the QoL -AD was not administered.

However based on the four cases where both proxy (family caregivers') ratings and individual ratings were available, data show that QoL-AD scores ranged from 28 to 40, reflecting the fact that most people enjoyed a reasonably good quality of life. The mean QoL-AD score for people with dementia was 34 (range =29-38) and for family caregivers was 34 as well (range = 28-40)[6]. In general physical health, family, marriage and friends were rated most highly. Memory and ability to do chores around the house and have fun were the items on this scale most negatively rated.

Table 2: Responses of persons with dementia to QOL-AD (N=5)

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

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[6] The numbers here are very small hence findings must be interpreted cautiously.

Table 3: Responses of Family Caregivers to QoL-AD (their perceptions of their relatives quality of life)* (N = 9)

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

* Numbers of family caregivers per category across 12 QOL domains

From the perspective of caregivers, the QOL-AD scores ranged from 28-40, with an average of 34 and a median of 35. One of nine carers interviewed was not a family caregiver but completed the QoL-AD.

6. CONCLUSIONS

In conclusion, data from this evaluation show that LWwD Stillorgan-Blackrock was successful in achieving its aim of developing new recreational and social activities for the person with dementia and providing a break from the usual routine for the person with dementia and for some family caregivers. It provided innovative transport solutions to enable the person with dementia travel to such activities, and at the same time offered some respite to those family caregivers who needed it. Findings show how the intervention clearly brought together different community voluntary and statutory groups (HSE allied health staff, Southside Partnership Groups including Community employment) to raise awareness of dementia.

The project therefore reflects a community response to dementia and the data showed the way in which the interventions provided, addressed a variety of complex needs such as the need for social inclusion, meaningful activities, psycho-social stimulation, and physical exercise. New and importantly “normalised” recreational and social activities were developed which provided innovative transport solutions to enable people with dementia to commute to such activities. Overwhelmingly, however, it was the structured yet integrated aspect of the programme (physical exercise, psycho-social stimulation, carer support groups, transport provision, and key contact workers) which family caregivers found most appealing.

The qualitative data provide compelling evidence of how a programme like this can yield mainly positive outcomes in the short term for both people with dementia and for their family members, albeit at times different outcomes for the different client groups. Through the carer support group and through the key worker principle adopted (a knowledgeable person available by phone) this programme connected family carers into a support system which from the majority of accounts made home care a little easier for them. For many, it opened up opportunities for carers to link into other services. On the other hand, for those diagnosed with dementia, the exercise programme itself and the opportunities it afforded them for "normalization" and for on-going psycho-social stimulation with cognitively intact people was welcomed.

This review of the programme provides some evidence of areas where LWwD Stillorgan-Blackrock could now be improved. Suggestions here should be interpreted cautiously as it needs to be remembered that the number of participants involved in this evaluation were very small and the sample was not random hence the data is likely to be biased. Nonetheless the data provide preliminary evidence that the programme could have been even more successful had assessment of these mens' and womens' physical, sensory and cognitive needs taken place prior to their enrolment on the programme. The data for example showed that in some cases the exercise programme was too strenuous causing some to withdraw either permanently or temporarily and conversely in other cases it was not sufficiently demanding. There was also some evidence albeit very limited that some families would have liked additional supports that would have meant bringing their relative on outings and more help at night and at weekends. Others would have liked the social aspect of the exercise programme to be further expanded. Once again it needs to be acknowledged that data for this evaluation was collected in the weeks immediately following the introduction of the new respite service. Changes as suggested by clients have now been incorporated into the revised programme and the latter has been re-developed based on this valuable feedback and from ongoing review.

In keeping with the South Tipperary Dementia Support Worker Initiative (DSWI), the data show that LWwD Stillorgan-Blackrock was not a substitute but largely a supplement for other more traditional forms of respite support such as day care, (also highly rated) or residential respite since most of the sample continued to avail of these services. Several other similarities were found in the data on LWwD Stillorgan-Blackrock when compared with findings from the DSWI. Most notable was the fact that QoL-AD mean scores were very similar across the two projects (mean self-rating QoL-AD score for DSWI was 34 and in LWwD Stillorgan-Blackrock was 35), and caregiver burden as measured by the ZBI were also similar - LWwD Stillorgan-Blackrock was 29 and for the DSWI was 32. The most notable difference between the two forms of respite was that one was hugely individualised and delivered from home, whereas LWwD Stillorgan-Blackrock was a group activity and delivered in local familiar community settings.

In conclusion, the LWwD Stillorgan-Blackrock exercise programme presents a valuable and innovative approach to respite care for community-dwelling people with dementia and their carers. As demonstrated in this study, LWwD Stillorgan-Blackrock met these people's needs for social stimulation, meaningful occupation and community integration. The overall programme reflects very effective partnerships in care. The actual service was provided by skilled staff who in many cases adopted a quasi case-worker role and the service was offered in an integrated and structured way. In particular, the programme's foci on 'normalising' respite supports for those affected by dementia and avoiding the separation of people with dementia from their families/communities was novel and clearly distinguished LWwD Stillorgan-Blackrock from more traditional respite services such as day care or residential respite care. As participants' rich narratives powerfully revealed, LWwD Stillorgan-Blackrock is an important and much-needed addition to the under-developed community support service landscape for people with dementia and their family caregivers in Ireland.

Bartlett and O'Connor exhort us to think and talk differently about people with dementia (Bartlett & O'Connor, 2010). They suggest that by way of broadening the dementia debate a social citizenship framework should be applied. Components of the social citizenship framework they argue include growth, social positions, purpose, participation, community and freedom from discrimination. This conceptual framework is an extension of Kitwood's recognition of the psychological needs of people with dementia. The Bartlett and O'Connor framework recognizes the person with dementia as an active agent with rights, history and competencies.

The model of respite trialled and evaluated in this report clearly reflects this shift in thinking and in ideology. It is a model which in our view offers people with dementia purpose, allows them participate, encourages growth and freedom from negativity stigma, embarrassment and nihilism. In summary it is a model which we would argue empowers the individual with dementia and reflects a community and societal response to the challenge of dementia. It is a model which in our view should now be emulated and expanded across the country.

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