



THE ALZHEIMER
SOCIETY *of* IRELAND



Social Space: Equal Place

The Social Club Model of
Dementia Care:
A Research Report



Catherine Keogh
Gráinne McGettrick

The Alzheimer Society of Ireland is the leading dementia specific service provider in Ireland. Founded in 1982, by a small group of people who were caring for a family member with Alzheimer's disease or a related dementia, today it is a national voluntary organisation, with an extensive network comprising 22 Branches, 33 Day Care Centres, 28 Home Care Programmes, 28 Support Groups, 3 Social Clubs, and one overnight Respite Centre. The Society also operates the Alzheimer National Helpline offering information and support to anyone affected by Alzheimer's disease / dementia.

The vision of The Alzheimer Society of Ireland is:

- a world where dementia can be prevented and cured
- where stigma of the person with dementia is challenged and overcome
- where those who live with dementia have all they need to live happy and fulfilling lives.

What we do:

- campaign for better services
- provide a confidential, freephone Alzheimer Helpline: 1 800 341 341
- run nearly 94 local specialist services for people with dementia and their carers across Ireland including day care, home respite, overnight respite, social groups, support groups, advocacy and counselling services
- provide carer information and support
- provide information service and website: www.alzheimer.ie
- raise public awareness through national and branch activities and campaigns
- innovate and pilot new specialist services and supports
- commission and collaborate on social and therapeutic research projects
- fundraise to support our work
- provide opportunities for volunteers.

What you can do:

- become a member
- advocacy – campaign with us in public affairs and media arena
- volunteer time, resources or expertise locally or nationally
- become a private/corporate donor or participate in fundraising events.

For further information about membership or any other of our activities please contact: The Alzheimer Society of Ireland, Alzheimer House, 43 Northumberland Avenue, Dun Laoghaire, Co. Dublin. T: (01) 284 6616. F: (01) 284 6030. E: info@alzheimer.ie.





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Executive Summary

The social club is a unique response to the needs of people with dementia and their carers in the context of dementia service provision in Ireland. Social clubs are a gathering of people with dementia and their carers (usually the spouse but not exclusively) who come together in a social context to support each other, share experiences and enjoy each other's company.

Current literature supports the development of the social club model and its philosophical base adopted by the Alzheimer Society of Ireland. The caring experience influences the well-being of the carer and person with dementia. Provision of social support for people with dementia is central to best practice and this support is best provided in a way that supports the couplehood of the person with dementia and their spouse. The social club model is an effective way of meeting this need and is an innovation in dementia care practice in Ireland.

The Alzheimer Society of Ireland's first social club opened its doors in Bray, Co. Wicklow in 2005. Since then two other clubs have been developed and all three clubs have been sustained. They offer a range of benefits to their members and provide additionality of service provision. Central to the success of the model is the availability of staff with the necessary range of skills and level of empathy to facilitate the clubs.

This research examined the establishment of the social club model within the Alzheimer Society of Ireland and specifically aimed to:

- Document the development of the social club model
- Capture what has been learned since the establishment of the first social club
- Identify best practice guidelines for social clubs based on this learning
- Promote the adoption of this model in other regions

Key findings that emerged from the research were:

- The club provided a space for worry-free socialising of people with dementia, their spouse/partner and others
- The club provided a forum for sharing caring strategies and receiving support
- The club promoted the social network and skills of the person with dementia
- The club addressed some of the social isolation felt by carers and their partners

Key factors that were crucial to the success of the clubs were

- The relaxed, informal nature of the clubs
- The members' active involvement in the running of their own club
- Staff that are skilled in dementia care, are empathic and embrace the philosophy of the club
- Outings and social occasions

The overriding theme that resulted from this research study was that the social clubs offered their members unique benefits, thereby enhancing and adding to the range of services provided by the Alzheimer Society of Ireland. Recommendations for the future include:

- Securing specific funding for the social clubs
- Adoption of the model in other regions to augment existing services
- Continued consideration of the 'couple' in all aspects of service delivery and their need to be socially supported together.

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Acknowledgements

The clubs outlined in this report grew from innovative staff members and volunteers recognising clients' needs and thinking differently about how to support them. The development of this model owes much to these pioneers, and to the growing body of literature in Europe on models of practice that include both the carer and person with dementia. It owes much to the facilitators who recognise that building relationships is key to the clubs' success. And of course, it owes much to the members of the clubs who allow us to witness and support their journey.

The authors wish to acknowledge all those who contributed to the research process - the pioneers, facilitators and members of the clubs. We thank you for sharing your views on the clubs and allowing us to reflect those views in this report.

Foreword

“Interdependence is and ought to be as much the ideal of man as self-sufficiency. Man is a social being”

(Mahatma Gandhi 1869-1948)



Maurice O'Connell
Chief Executive Officer

It gives me great pleasure to introduce ‘**Social Space: Equal Place - *The Social Club Model of Dementia Care***’, in which we explore the impact of a dementia friendly social network on both the person and their carer/partner.

The Social Club Model is a unique and organic response to very fundamental human needs - those of belonging, support and being in relationships with others. It is based on a principle of recognising the needs of the individual as a social being first, within the parameters of their journey with dementia. It provides a safe, easy, social space, within which the person with dementia, their carer, our volunteers and staff meet as equals to choose a direction and journey together.

This report stimulates reflection on how we can embrace and support the ‘couple’ as they live with dementia. It provides signposts to better plan how we respond to the needs of people with dementia and their carers. Most of all, it provokes our consideration on what is to be human and have needs of belonging; safety; having fun; and of friendship. These needs do not change with the onset of a diagnosis of dementia.

Through this reflection we can improve our insight of the experience of dementia and how better we, as dementia care providers, can support this experience, so that each and every person can live their lives as they wish.

A handwritten signature in cursive script that reads "Maurice O'Connell".

Chapter 1 Introduction and Background

1.1 Introduction

The Alzheimer Society of Ireland (ASI) opened its first social club in Bray, Co. Wicklow in 2005. This new model of service provision has now expanded to two other locations - Dublin and Athy. The Society engaged in this small scale research to:

- Document the development of the social club model
- Capture what has been learned since the establishment of the first social club
- Promote the use of the social club model in other regions.

This report aims to inform and guide the future development of the social club model in ASI.

1.2 Aim of the Research

The overall aim of this research was to document the emerging role, function and operation of the Alzheimer Society's social club model. The specific objectives were:

1. To examine the origins and genesis of the social club model and place these in the overall context of ASI services
2. To provide an explanation of how the clubs are established and run
3. To present the core elements of what constitutes a social club for people with dementia and the carer with reference to the 'unique' elements in the ASI model
4. To identifying what resources are needed in order to optimise the social club experience
5. To examine the opinions and experiences of members of the clubs and staff
6. To explore some of the key development issues for the future

1.3 Methodology

The research was an exploration of the social club model developed by the ASI and was carried out to document the Society's experiences of the model to date. A number of methodologies were employed to gather the data.

1.3.1 Study Design and Procedure

The study was a small scale study with a mixed quantitative and qualitative methodology. It aimed to gain insights from the experiences of members of the clubs and staff of the design and implementation of social clubs. The sample chosen comprised all current social club members and staff, as well as key stakeholders who were instrumental in their development. The process of gaining information was as follows:

1. A postal survey was administered to the social clubs facilitators (n=5): all of whom responded.
2. A postal survey was administered to service users (n=21): 33% response rate
3. A member-checking session was held with one of the social clubs where the initial findings were presented and further discussed.
4. One-to-one opened ended interviews with other key stakeholders¹ (N=3)
5. Data from a previous internal audit of one of the clubs was included in the analysis.

1.3.2 Data Analysis

The data gathered from all of respondents, member-checking group and stakeholder interviews were collated and examined for key themes. These key themes are presented in the findings.

¹ These included the CEO, Regional Manager and a Volunteer who is facilitator of a number of support groups.

1.4 Summary of Chapter:

- This small scale research documented the development of the social club model of dementia care by ASI, examining their role, function and operation;
- Both qualitative and quantitative methods were used and the findings are explored under key themes.

Chapter 2 Literature Review

2.1 Introduction

This chapter presents a brief review of the literature and presents key concepts which the social club model addresses. The literature search was refined to describe:

- Dementia and its effects on the individual
- The related effects of dementia on caregivers
- Social support in the elderly and the caring role
- Couplehood and couple identity
- The Alzheimer Café Model and emerging models of care

2.2 Dementia and the Effects on the Individual

Dementia is the term for a group of largely incurable, progressive conditions that break down the structure and chemistry of the brain, affecting the person's ability to remember, understand and communicate. It has a life-changing physical, emotional and mental impact on the person, their primary carer and family. "Dementia causes the person to experience gradual powerlessness and estrangement from their surroundings, and is a confusing and frightening experience for the sufferers themselves and their family and friends" (Miesen, 1999, p7).

Maintaining personhood in the advance of cognitive impairment is considered best practice in dementia care. Personhood is defined as "a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being. It implies recognition, respect and trust" (Kitwood, 1997, p8). The maintenance of personhood constitutes a key role in the caregiver's lives as the dementia progresses. Keady (1999) would describe that in most caring relationships the main motivation of the non-affected spouse throughout the process of 'working' was to maintain the involvement of

the person with dementia by creating ways in which their sense of agency and self could be sustained for as long as possible.

2.3 Dementia and the Effect on Caregivers

Caregiving is part of our lives and the giving of care in an attempt to protect or enhance your loved one's well-being is an intrinsic quality of primary relationships. We treat caregiving as a separate role when one partner becomes overwhelmed with an extraordinary and unequally distributed burden, such as when a diagnosis of dementia occurs. In this instance, caregiving develops into a dominant, overriding component that can occupy the entirety of the relationship. Caregiving in this sense is "potentially a fertile ground for persistent stress" (Pearlin et al, 1990, p583). As progressive dementia involves changes in patients' behaviour as well as cognitive and functional abilities, dementia caregiving can be considered as a process that demands continuous adaptation to change. (Perren et al, 2006)

Generic studies on the concepts of caregiving report that the caregiving role is associated with increased stress. (Upton et al, 2006; Beeson, 2003; Waite et al, 2004; Gallagher-Thomson et al, 2001). In relation to dementia, studies have repeatedly shown that caregivers of those with dementia show an increased rate of stress, depression and loneliness than those caring for non-dementia patients. (Bertrand et al, 2006, Hellstrom et al, 2005, Pinquart and Sorenson, 2006, Donaldson et al, 1998). Waite et al, 2004 estimate that depression among caregivers of people with dementia occurs between 40-60% of the population compared with the 8% incidence of depression in non-caregiving persons.

There have been attempts to describe why the rate is so much higher in caregivers of people with dementia and some interesting hypotheses have been proposed. Pearlin suggests that "conditions of chronic and progressive impairment lead demented people to become increasingly dependent on others

for the satisfaction of their basic needs, and the sheer dramatic and involuntary change in caregivers daily lives is a major source of stress” (1983, p112). Other authors suggest that “the nature, extent and duration of the dementing process breeds an atmosphere of isolation combined with a sense of aloneness for spouse carers, both in terms of their spousal relationship, and the wider social world” (Upton et al, 2006)

Therefore the recognition of additional stress in caregivers of those with dementia is acknowledged in the literature. Also acknowledged is that buffering of stress and increased support in the caregiving spouse can influence the course of dementia in the person who has received the diagnosis. “Caregivers may have a much more important and dramatic influence on the clinical course of the person with dementia, particularly in variables such as the frequency and severity of their behavioural problems and timing of their placement in an extended care facility” (Suk Lee et al, 2006, p784)

Sustaining the caregiver in their role can influence the experience of dementia; therefore any consideration of the support of the person with dementia must automatically include their caregiver. Documented widely is the fact that many caregivers of people with dementia become socially isolated. Not only have elements of their significant relationship changed, but they may also have lost access to their social support networks; a natural stress-buffering tool.

2.4 Social Support and Caregiving

The concept of social support was first articulated by Cassel (1974) and Caplan (1974) who identified the importance of social ties in coping with crises, life transitions, and deleterious environments. Cobb subsequently determined that social support has ‘stress-buffering’ properties, which can have an ameliorative effect on health and social functioning. (1976, p73).

One of the first definitions of social support described it as “emotional support, advice, guidance and appraisal, as well as the material aid and services that people obtain from their social relationships” (Ell 1984 p134). Sherman & Boss (2007) state that “social support is understood as a protective resource against a large array of physical illnesses as well as critical for recovery and rehabilitation, mental health and subjective well-being” (p248).

In specific relation to the elderly, the “buffering effects of social support were the most salient when the elderly people encounter problems with their health” (Lu & Chang, 1997, p473). A study in Taipei noted that among the elderly there, social support was the most important predictor of life satisfaction, more significant even than self reports of health (Huang, 1992).

Becoming socially isolated within an already stressful situation serves to increase the perceived stress and strain and reduce caregiver coping ability. Studies have found a pervasive and profound effect of social support on health of the elderly, therefore interventions targeting social support enhancement may prove to be both economical and effective. However one would surmise that interventions which involve both the caregiver and person with dementia would serve to be equally if not more effective, as they address the concept of social support plus a concept widely written in the literature - couple identity.

2.5 Couplehood and Couple Identity

The wider effects of social support and the resulting social isolation that is documented in dementia caregivers are significant. However, what appears to be more significant is the struggle caregivers have in losing one of their most significant relationships, that of their spouse. “Dementia appears to reduce the ability of the person with dementia to provide emotional and practical support to their spouse” (Baikie, 2002 p291)

Beeson reports that “the longing for interpersonal intimacy stays with every human being from infancy throughout life; and there is not a human being who is not threatened by its loss” (Beeson, 2003, p141). The loss of companionship, loss of reciprocal exchange of affection, loss of a confidant, especially in the marital dyad - can affect quality of life for spouses of people diagnosed with dementia (Beeson, 2003). Loss of identity was also reported, particularly when that identity was strongly linked to the identity of the couple.

This highlights the concept of couple identity. Couple identity is referred to as “being part of a couple as part of one’s identity” (Badr et al, 2007, p213). The ‘I’ becomes the ‘We’ and much of one’s identity can become linked to the identity as a couple. Losing this identity is a real threat to the caregiver’s well-being. Not only are they dealing with increased stress in managing a chronic illness, but they are losing the one confidant they would have talked to about it. Loneliness in itself is “not caused by being alone, but a response to the absence or loss of a definite needed relationship of a close attachment figure” (Weiss, 1973, p 54).

“Being part of a marriage union in our society builds on these human needs. Marriage often represents the single most influential and sustained relationship in one’s life. Sharing experiences over a lifetime helps to define and maintain one’s individual need for human, interpersonal intimacy as well as defining who we are as an individual and a partner in the marital dyad” (Beeson, 2003, p 141). Supporting and celebrating the marital dyad should therefore be considered when developing services for people with dementia. The benefits are potentially two-fold: to embrace the identity of the couple, thereby recognising personhood within the context of couplehood; and to provide social support and its benefits to the caregiver.

Embracing the couple’s identity does much to maintain the personhood of the person with dementia, as it is inextricably linked to their spouse. In fact, much

of what has been written about dementia centres on the concept of personhood and its relation to social being. Kitwood was a proponent of no-one flourishing in isolation and that relationships are a key factor in “maintaining a sense of self and personhood” (Kitwood, 1997, p8). Therefore, doing things together for the couple is an essential component of who they are, both individually and together. Facilitating ways in which both persons can receive support and recognition as a couple, appears to facilitate much of the benefits outlined from social support. One such model already in existence that addresses the marital dyad is the Alzheimer Café Model.

2.6 The Alzheimer Café Model

There is a limited amount of literature available on the Alzheimer Café model which in turn is mainly descriptive in nature. The initial concept for the Alzheimer Café emerged in the Netherlands in the late 1990s. It was pioneered by Dr. Bere Miesen (a clinical psychologist working in the field of old age psychiatry) in conjunction with the Dutch Alzheimer Association. In his dealings with people with dementia and their families, Miesen observed that talking about the condition/illness, even between partners or within a family was a taboo subject. Making dementia discussable and providing information about it and its consequences is very important for the acceptance of the condition. Miesen recognised that it would be good if all those involved could meet each other in a relaxed forum to exchange experiences and talk about dementia. (Miesen, 2001). The Alzheimer Cafes are meeting places to help people with dementia and their families to learn how to respond to and live with dementia. In short, the Alzheimer Café can be regarded as an intervention with aspects of both education and support”. (Miesen, 2001)

The value that the Alzheimer Café brings is that “by talking about the problems that having dementia brings, persons and families can better manage their own situations. Making the illness discussable gives the person with dementia the

feeling of being able to influence his situation. The family sees that they are not the only ones with feelings of powerlessness and dislocation.....The visitors feel that they belong and find recognition and acceptance. That in itself is unique”. (Miesen, 2001: 3) A broad range of people can attend the cafe - people with dementia, their families, relatives, friends, health and social care professionals, paid carers, students and volunteers. The Café covers a range of activities including the more formal element, for example a presentation to the informal elements of music, refreshments and socialising.

2.7 Adaptations of the Alzheimer Café Model

Many other countries adopted the Alzheimer Café model to suit the cultural and social context. The German Alzheimer Association adopted the model by moving away from the Dutch information model to an activity-based model. The Belgian Alzheimer Association describes how their cafés use some of the German and the Dutch models and how they place a central importance on ‘conviviality’, creating a feeling of belonging and breaking the social loneliness of the person with dementia and the family. (Alzheimer Europe website www.alzheimer-europe.org)

The Alzheimer Café concept has also emerged into dementia care practice in the UK. In Hampshire, they have followed closely the Dutch model. Redwood describes the Hampshire café as

“An evening out for everyone interested in Alzheimer’s disease and related illnesses. It’s for people with dementia, their spouses, children, grandchildren, friends, carers and healthcare professionals.....The theory is that people feel better when they realise they’re not alone”. (Redwood, 2001: 9)

Redwood contends that the cafes work because of the commitment and interest of key families, individuals and professionals. These are people who know about the dementia process from first hand experience and are not shy of talking about it. In 2002, the Alzheimer’s Australia opened their first Memory Lane Café in Melbourne. The café expressed the common aim of

providing mutual support, preventing isolation and providing a forum for informal advice. Mather (2006) asserts that the cafes are particularly beneficial to people in the early stages of dementia. They are generally aware of their changing cognitive abilities and as a result can lose confidence and trust in themselves. This can lead to social isolation, loss of contact with friends and the giving up of past social activities. By encouraging people to find strategies to manage these cognitive changes, people with early stage dementia are encouraged to regain contacts within their community and to take up activities that they had previously enjoyed or to try new activities.

Further variations on the model have emerged and are described in the literature. Sweeting (2001) describes a 'café event' where a once off, whole day event was organised around the theme of "every day matters". It involved a very broad range of inclusive and participative activities highlighting the value of everyday life and the enjoyment that is to be had. In Southampton, funding was secured for a dementia café which was renamed the Woodside Supper Club. The club offered the person with dementia and their carer the chance to enjoy dinner together. (Reavell, 2004) It is clear from the literature that the frequency and nature of the meetings varies but the monthly interval is the most popular choice. The timing also varies -with some held during the day, others in the evenings, some at weekends, others on week days.

There are many other 'support group' type models reported in the literature, with a growing number of user-led groups. These models share elements of the Alzheimer café model in terms of their philosophy of addressing the challenges of living with dementia as well as looking at people's need for socialising with support.

2.8 Conclusion

The scope of this review was limited to literature of direct relevance to ASI's social model. The key findings from the literature review were:

- The literature on dementia, social support and caregiving is significant, as is the literature on emerging models of service delivery.
- Social support plays an important role in dementia care.
- The concept of couple identity was highlighted and it's relevant to dementia care practice.
- New models of practice have been developed internationally and these can be adapted to be culturally appropriate to the unique needs of different populations.
- The Society's social club model is a unique response to the context of dementia service provision in Ireland.

Chapter 3

Findings of the Research

3.1 The Origins and Genesis of the Social Club Model

The social club model emerged as a response to meet the social support needs of people with dementia and their carers, identified by staff working within ASI's services. The three service development needs that were identified within the ASI were:

1. To cater for both the carer and the person with dementia
2. To address the social isolation experienced by both the person with dementia and the carer
3. To cater for people in the earlier stages of their dementia

No service existed to cater for both the carer and the person with dementia together (very often a husband and a wife). The Society's services were primarily designed to give the carer respite through either provision of day and home care services. In particular, the day care service aims to meet the needs of the person with dementia in a centre away from home while the carer remains behind. The home care service is designed to provide support to the person with dementia at home while relieving the carer from their caring duties.

In addition to the gap in services, anecdotal information coming through the carer support groups at the time was that there was an overwhelming sense of social isolation experienced by both the person with dementia and the carer. They often experienced an increasingly limited social circle and diminished opportunities for engaging in suitable and appropriate social activities. Such anecdotal information is now supported by evidence of an exploratory research conducted for the Society in 2006 on the perceptions of stigma in dementia (Nolan et al, 2006). This research highlighted that

“Several components of stigma emerged as critical concerns and experiences of the participants: social unacceptability, social isolation, policy and service disconnects, structural discrimination and devaluation” (pg 92)

The report concludes;

“The findings of the study clearly indicate that people with dementia and their carers are often subject to attitudes and experiences which encourage isolation from usual support networks, social distance from others in society, difficulties in navigating the available systems and services, and threats to self-esteem and personhood. These are experiences usually associated with belonging to a stigmatised group.”

There were no services apart from mainstream day care centres that catered for people in the earlier stages of their dementia. The existing ASI services, more often than not, came into play when the person is experiencing a significantly increased level of cognitive decline.

In discussing these service development needs, the Alzheimer Café model was identified as a possible option. As was the case in other countries, the model was adapted to suit the Irish context - it was not to be called an Alzheimer Café given some of the possible negative connotations that it may construe. It would have an entirely ‘social’ agenda with support being provided in an informal way. The model would differ in relation to other ASI services in that the ‘service users’ would run the service. The staff would play a facilitator’s role in the group. It was to be flexible, informal and fun. The philosophy was to reflect the building of relationships and maintaining the ‘couple’. The Club would be fully voluntary in nature and provide peer support in a purely social environment.

3.2 Profile of the Clubs

The three social clubs are held in Bray, Athy and Rathfarnham. The clubs are known locally as the Monday (Athy and Bray) and Friday (Rathfarnham) clubs. Bray and Rathfarnham are staffed by two ASI employees; Athy is staffed by one with occasional assistance from a volunteer member of the society. Five regular couples attend the Monday club in Bray, with up to two other couples dropping by. The Monday club in Athy serves four regular couples with another two dropping by. The Friday club in Rathfarnham serves eight regular couples with up to four more dropping by. Outings are held in both the Bray and Rathfarnham clubs due to availability of a bus. Athy currently does not carry out outings but plans are afoot for this to occur in the future. The mean length of time that respondents attended the clubs were for 13.5 months, giving a fairly sustained cohort of members.

3.3 Findings of the Research from the Staff and Key Stakeholders Perspectives.

3.3.1 The role of Staff in the Social Club

The staff reported on what their role was in the club - without exception they all cited themselves as 'facilitators' of the club. This facilitation included a significant amount of duties such as providing information, organising trips and planning activities, identifying potential participants, welcoming club participants and providing support by listening and advising. The staff also help out with all the practical elements such as preparing the room, getting the refreshments ready and helping with personal care.

3.3.2 Differences with other ASI Services

All the current staff involved in the facilitation of the social clubs work in other ASI services. They identified that some fundamental differences between the social club model and other ASI services.

The fundamental difference identified was that the carer and person with dementia were together. The informal nature of the clubs was highlighted as was the relaxed atmosphere and flexible nature of the service. As one staff member puts it

“It is a very family oriented type setting; everyone is the same; people chat to others; it’s friendlier, with everyone on first names. There are no bosses; they do what they want to do” [Q2]

Another staff member reflects on the relaxed atmosphere saying:

“It’s casual, no huge structure. It is purposely set like this to create atmosphere of ease and relaxation. It’s far more relaxed than other settings” [Q3]

Another member of staff has a similar reflection:

“It’s a social setting for client and carer, loose structure, no routine, an open door policy with members involved in decision making” [Q4]

In terms of placing the club in the overall context of ASI services, the staff and stakeholders made a number of pertinent comments. As already highlighted, the differences between this service and other ASI services are clear. However, the social clubs were viewed by some as a good transition phase for the person with dementia and their family to day care or home care services. The Clubs allow the client/carers to build a trusting relationship with the organisation and they gain an understanding of what the services are about.

In some cases, the club fills a gap where there was no day care service available. In other cases, the club was seen as complementing the home care and day care services. In practice the clubs can fulfill both roles of being complementary or substitute.

3.3.3 What is Needed to Set up and Sustain a Club?

A range of items were identified by staff definitely needed to set up a club including all the practical elements such as an accessible venue with plenty of space, equipment, games and transport (to and from venue and for outings). In addition, there needs to be enough interested members to attend with skilled personable staff.

In order to sustain the club it was seen that there needs to be a core group of regular members who attend so that a rapport can be built in the group and between the group and the staff; the group needs to be able to meet the member's need, and members need to be treated with dignity and respect. There needs to be an openness and friendliness as well as a sense of shared empathy. The environment needs to be supportive and enable people to connect with each other and if possible build friendships. Concrete examples of where building friendships were provided; two of the couples from one of the groups went on holidays at Christmas time together; another two couples meet frequently outside of the club now. Enabling all the members to have an input was also identified as being important to sustaining the club.

3.3.4 Decision Making and the Clubs

One of the ways in which the clubs differ from other ASI services is that service users themselves make the decisions regarding the running of the club. Staff perceive themselves as facilitators and there are no 'managers' or 'bosses' in charge. Ideas are discussed and the group comes to mutual agreement about the club and the activities.

3.3.5 The Success of the Clubs

When asked to reflect on the success of the clubs, the staff and other stakeholders responded in a variety of ways. However, there was unanimity that staff was the key to the success of the social clubs. The skills that were

identified as being needed in the staff were “*friendly, interested staff*” [Q3] and “*understanding and emphatic staff with good communication skills*” [Q4] One of the stakeholders commented that “*The skill and charm of the staff is crucial*” [SH3]

Consistency of the staff attending was identified by one of the stakeholders as being important, commenting that “*commitment and consistency in terms of the staff attending is needed*” [SH3]. This trait is supported by the Alzheimer Café literature. The format of the club was also seen as crucial to the success: “*.....formality loses people; people are lonely and want to chat to someone in the same boat; the chat and the cuppa are so important*” [SH3]

Apart from the staff, the need for a good accessible venue, with appropriate facilities as well the availability of transport was needed to enable the clubs to be successful. In addition, keeping the interest up among the members, keeping them involved in what goes on and supporting the members through changing circumstances were all identified as being central to the success.

3.3.6 Benefits of the Clubs

Staff and stakeholders alike identified the benefits of the clubs. The clubs meet a number of needs and address the social isolation that many carers and people with dementia experience. The need for social interaction, friendship and support for the participants as individuals as well as a couple are all being met by the club. The benefits of the sharing and empathy are highlighted by staff:

“To be able to share experiences with people in similar situations is priceless; great friendships have been born and we as a group have shared some very happy and emotional days together” [Q3].

Another staff member comments

“people meeting others in similar circumstances and finding hope in what a lot believe to be a helpless situation and realising they are not alone. It’s a positive setting” [Q5]

One of the stakeholders says

“Forget the formal stuff. People are lonely and they want to talk to others in the same boat. As word gets out, people realise there’s no intrusion or commitment needed” [SH2]

The social outings are a great source of enjoyment and *“worry free”* for everybody. There is a complete understanding in the group so unusual behaviour is understood and not a source of stress. The carer doesn’t have to ‘worry’ about anything - there are enough people around to support them.

In addition, the maintaining of social skills, self esteem, and personhood for the person with dementia is enabled. *“The person with dementia still feels that they have a contribution to make from a social point of view and this is very important for their self esteem” [Q3]*. Another staff member remarks that *“the clubs keep the client [person with dementia] in contact with others and this helps to maintain their social skills” [Q2]*.

One of the stakeholders identifies that the clubs play an essential role in the often forgotten social aspect of people’s lives and emphasises the *“togetherness”* element as being critical. In addition, the carers learn caring strategies from each other, building up mutual trust and friendship. [SH2] Furthermore, it is identified that *“peer education is happening all the time” [SH2]*.

3.3.7 Overcoming Some Difficulties

Staff were asked to identify any difficulties that they had with the social clubs. In one area, sustaining the numbers was a difficulty and the facilitator addressed this by putting an article in the local paper. The facilitator also continues to encourage suitable couples to attend when she makes home visits. Another difficulty identified was coming up with new ideas all the time that was suitable and appropriate for everybody in the group. The need to continuously gather information, keep up-to-date with local activities and facilitating the group to come up with ideas were strategies used to address this. Apart from the more logistical difficulties, a more psychological difficulty was identified by a staff member who indicated that a challenge was “.....*getting people not to be embarrassed about meeting others in the same situation*” [Q2]

3.3.8 Unsustainable Clubs

Attempts at setting up and establishing a number of clubs in North Dublin were made in 2006 - in Drumcondra and Cabra. The clubs were not successful in sustaining themselves. In establishing the reasons why they were not successful, the stakeholders identified a number of reasons why. Firstly, there was a relative lack of knowledge among potential members to attend. The reason suggested for this is that the ASI network is underdeveloped in the north Dublin area. In addition, the day that the club was scheduled in Cabra was the day that clients from the area were attending an ASI day care centre in the city centre or a Health Service Executive service so there was a clash with the club. In Drumcondra, a small number of people came but in a short space of time one person went to day care and another person who attended was at a fairly advanced stage and in hindsight, the facilitator felt that the person was too advanced to be able to operate in the group. In addition, the venue was identified as an obstacle. The venue chosen for the two clubs was a local authority older people’s housing unit. It was suggested that perhaps

some members perceived the location negatively and that it in turn impacted on the attendance. Finally, the lack of transport was also identified as being an issue. It was pointed out that while the clubs did not work out at that particular time, it is clear that at some other stage in the future that it should be attempted again and that they may well be sustainable.

3.3.9 The Future of the Clubs

Staff and the stakeholders were clear that the model is one that works, reaps multiple benefits, is excellent value for money and one that should expand and develop throughout the country. One staff member commented *“This should become a regular service that everyone can access; you can see the stigma leaving the family and the person with dementia becomes a person in their own right”* [Q2]

The expansion of the clubs was supported by a staff member who suggests that the clubs should operate Monday to Friday so that people can have a choice of club to attend. In addition, expanding them into the evenings was advocated with one staff member indicating that there is a demand from the group she works with to go on a short break together. The other stakeholders' views concurred with the staff on the basis that the clubs meet a different set of needs.

The expansion of the model is desirable but the Clubs need to retain their uniqueness and informality. There is a need to sell the idea to staff in the organisation as key staff are needed to drive the initiative. The future development of the club requires an investment in the organisation's human capital, particularly investing in training in facilitation skills for care workers. In addition, the stakeholders argue for additional resources for the Clubs to come through the existing service level agreements with the HSE.

One of the stakeholders suggests that the model should be rolled out around the country with emphasis on areas where there are no ASI day care services initially. Equally important is that certain things should not happen; *“there should not be too much formality and the emphasis should be on the social aspect of the club with the members at the centre”*. [SH2] The suggestion was made by another of the stakeholders that the Society should use the existing home care structure to develop the model throughout the country. The Home Care Co-ordinator is best placed to know many of the people in the community and what the needs are. In addition, *“the building of relationships is key and good staff is the key”* [SH2]

3.4 Findings of the Research from the Members’ Perspectives.

3.4.1 Members’ Responses

Gaining the perspective of the members was carried out in two ways. Each member was sent a questionnaire to complete outlining their views on the social clubs. These views were collated and taken back to one group to member-check the results, and identify if they reflected the member’s perspective. A previous audit carried out by one of the social club facilitators and qualitative comments have been included below that are attributed to that audit.

Twenty-one questionnaires were posted and there was a 33% response rate. Of the responses, 90% were completed solely by the carer, and 10% completed by both. The respondent sample was across the three clubs. Members had been involved in the clubs from anywhere between 2 months and 20 months, with the mean attendance being 13.5 months. Many of the respondents were also using other ASI services such as home care and day care and other statutory organisations for support. The majority of the respondents had heard about the social club from the ASI services or personnel they had links with.

Only one respondent had heard about the club from an external source (Bridge Club).

3.4.2 Experience of the Social Clubs

The resounding response to the social club questionnaire was that it was a positive experience and people valued being part of it. The main areas highlighted were the opportunity to meet other people who had similar difficulties in a relaxed and warm environment and the outings.

People valued the *“interaction between carers and carees”* (QM1) and *“comparing experiences”* (QM3). One respondent commented that *“as a couple it allows us to meet others with similar interests”* (A2) and that *“it’s useful to socialise with people who have similar problems and share experience and ideas”* (A3)

The opportunity to meet other people also lessened the carer’s experience of social isolation *“it makes you realise you are not on your own”* (A4) and *“it gives support which helps to alleviate the feeling of being the only one in that position”* (QM2).

The club therefore facilitated not just an opportunity for social contact but a place where couples could meet and reduce the social isolation often felt by the carer.

The other main area of identification across the questionnaire responses was the experience of the outings. The outings were valued by all as an important feature of the social club programme. Due to transport difficulties it was not an integral part of all the social clubs, but where in use, the respondents were positive.

“outings with security of knowing support and help is at hand” (QM1)

Other comments on the social club experience included the relaxed atmosphere, the banter and friendliness of the staff. The normality of the cup of tea and tea-breaks was also very important. There were very few negative comments on the overall experience, and if commented on, related to transport issues, i.e. having to drive to the social club when a bus was not available.

In general the respondents felt they had a say in how their club is run, and suggestions for outings were agreed to by consensus and availability of transport.

3.4.3 Meeting Needs

Each respondent was asked what needs did the social club meet for them and were they met elsewhere or only by the club.

With regard to what needs were met, there was almost a unanimous endorsement that the needs for social interaction and support were met by attending the social club. There was an emphasis on the fact that they attended with their partner, and that people understood and supported the abilities of the partner.

They stated it also met their needs for keeping active, developing friendships and keeping in touch with what was going on outside of their world of caring. One person responded that they kept up with gossip and conversation by attending the club.

The outlet of the club also facilitated a break from the routine of the week. One respondent commented *“It is something to look forward to”* (A1) and *“it makes you get up in the morning with a purpose”* and it provided useful and practical access to information.

The majority of respondents stated these same needs were not met in other services, or not met to the same extent. Some respondents did not avail of any other services as of yet.

3.4.4 Requirements of a Successful Social Club

The overwhelming response to the basic requirements of a successful social club was the characteristics of the staff facilitating it. This was commented on by everyone who responded. Characteristics ranged from being caring, patient, obliging, friendly, sympathetic, understanding, kind and having a sense of fun. It appeared that the unique qualities of the staff, whereby they understood the complexities of the condition, possessed high levels of skill in communicating with people with dementia and developed relationships with the members, was the defining feature of the successful social club.

Secondary to staff as the most crucial requirement, was a comfortable venue, options of activities and outings were seen as an enjoyable extra.

3.4.5 Future Development of Social Clubs

When asked what the respondents would like to see included in the social clubs, a number of issues were raised that will help guide their development.

Increased and improved activity options were commented. Some respondents felt that longer outing times could give a better choice of destinations, and that increased transport capacity could support this. A common theme for respondents was the option of having invited speakers in to the clubs on a regular basis to discuss issues related to dementia as well as general hobbies and activities.

One respondent commented that the social clubs should be accessed by all families who wish to do so, and that symptoms such as incontinence should

not be prohibit someone from the club. Another respondent felt a purpose built venue centred in the local area would serve for families to drop into.

3.5 Feedback of the Results

Both researchers carried out a visit to a social club to feedback the results above and check if they reflected the experience of the clubs. The social club was lively and energetic with conversation flowing and the strength of the relationships in the group were obvious. In fact, placing a structure on the group to feedback the results seemed in itself slightly at odds with the relaxed nature of the group. However, the group were happy to reflect their opinions on the results. They concurred that the experience of the club was a very positive one, where the outings, social support and friendships formed were paramount. They agreed that staff are central to the running of the clubs, and although their own venue was less than perfect, they placed all the value on the relationship with the staff. They did feel that small groups work better, so as not to lose the person with dementia in the conversation and to engage them at an appropriate level. They felt that although the emphasis in the clubs was on fun, there was always a backdrop of a concerned atmosphere. The participants felt cared for and looked after within the nurturing environment of the group, and felt that everybody understands their circumstances, making it easier to interact. There was some debate about the idea of speakers coming in, reasoned again by the fact that the person with dementia may not always engage at this level. There was however, a recognition that a variety would help, as long as the person with dementia could engage. There was agreement that the outings could be a little longer.

Overall the member checking revealed that the questionnaires closely reflected the experience of the social club. They also revealed that the organic nature of the social club needs to remain, because what may work for one club may not for another. The dynamic between the couples and staff in each group is

what is significant and the activities and choices after that should be left to that group to decide upon.

3.6 Conclusion

The overriding theme of the results was that the social clubs offered the members many benefits that were unique to other services. The results are supported by the earlier literature, particularly as members emphasise the social support they receive from the group and the feeling of being equal. The inclusion of the stakeholders' interviews help to round out the discussion and highlight the factors that influence what sustains a club. Therefore it is not just the commitment of staff but the commitment of the members that make a club thrive. Fostering this sense of belonging in the members is key to development of the club.

Key findings that emerged from the research were:

- The club provided a space for worry-free socialising of people with dementia, their spouse/partner and others
- The club provided a forum for sharing caring strategies and receiving support
- The club promoted the social network and skills of the person with dementia
- The club addressed some of the social isolation felt by carers and their partners

Key factors that were crucial to the success of the clubs were

- The relaxed, informal nature of the clubs
- The members' active involvement in the running of their own club
- Staff that are skilled in dementia care, are empathic and embrace the philosophy of the club
- Outings and social occasions

Chapter 4

Conclusions and Recommendations

4.1 Introduction

This research examines the origins, workings and uniqueness of the ASI social club model. It also documents the development of the model and shares the learning to date. A number of important conclusions emerge from the research findings and are considered with reference to the available literature. The conclusions drawn are central to any further discussion on the future development of the social club model in the Society.

4.2 Conclusions

Common themes emerged in the research findings that indicated benefits to client, carers and staff. These themes are discussed below with additional consideration given to the broader policy and practice implications of the findings.

4.2.1 The Benefits of the Club

The research findings highlight the significant benefits for the members who attend. The feedback from all the research participants indicates that the club benefits the members in a number of ways by meeting a series of their needs. The list is substantial:

- Addressing social isolation
- Providing the space for worry-free socialising
- Maintaining a social network and social skills
- Sharing of carer strategies
- Providing support to one another in an informal social setting.

These experiences are identified in the literature as essential for the person with dementia and their family to cope with and live with the condition. The

literature acknowledges the need for people affected by dementia to share their experiences with others. This in turn provides an understanding for what is happening and that they learn strategies to respond to the dementia (Miesen, 2001).

The clubs are beginning to address the social unacceptability and social isolation that goes with living with dementia (Nolan et al, 2006). Social isolation can have a significant impact on people's lives. Very often voluntary withdrawal is practiced by those with dementia and their carers as a way to "protect the person from the gaze of the outside world" or "to ensure that the person with dementia does not find him/herself in a context unsuitable to their needs" (Nolan, 2006, p85).

4.2.2 Successful Clubs - Key Factors

The research findings in this study clearly indicate that a number of elements need to exist in order for a club to be successful. Central to the success of the model is the availability and willingness of staff that understand the model and have the level of skill, knowledge and understanding to operate the club in accordance with the philosophy of the model. A caring, empathic and welcoming approach are the core skills for the staff. In the Dutch Alzheimer Cafe model (Miesen, 2001, p8) indicates that the group leaders play a crucial role in the planning and running of the Café and they determine to a greater or lesser extent what the participants get out of it. In addition, there needs to be a core group of members who attend regularly. This gives a sense of stability to the club and allows people to grow friendships, as highlighted by Miesen (2001) and Redwood (2001).

4.2.3 Position within ASI Service Matrix

This research indicates that the ASI Social Clubs:

- Are flexible and responsive enough to meet the needs of people with dementia and their carer/partner in the community

- They can thrive either as a complementary intervention to existing ASI day and home care services or
- They can operate entirely independently of the existence of other ASI services.
- Either way they ensure additionality to present service and support provision.

4.2.4 Implications for Policy and Practice

Reflections on the findings from this explorative study have implications for practice and policy development in relation to dementia services.

Central to the success of the clubs appears to be the staff resource and the informality of the clubs. In fact, the very naming of the meetings as ‘clubs’ as opposed to ‘care’ or ‘service’ reveals much about their underlying philosophy. A social club may refer to a group of people or the place where they meet, generally formed around a common interest, occupation or activity. In fact being a member of a club, has an entirely different connotation to being a user or client of a service. Clubs denote membership and ownership of the same club. Without the members the club does not exist. The members are the club and the club is the members. This itself places the social clubs in a unique position as part of the overall service matrix of an organisation.

The other element that is central to the unique philosophy of the clubs is the integral involvement of the spouse/carer as an equal member of the club, in addition to the person with dementia. Embracing the couple and their identity as central to the structure is unique to the philosophy of the social club. On further reflection, it also becomes apparent that it is the involvement of the carer that allows the club to function as an informal club, thus differing from traditional models of service provision and their formality.

Provision of services for people with dementia alone, implies a duty of care and a level of responsibility on the part of the service. Hence, services have developed with policies and guidelines which largely focus on documentation, and other legal requirements related to this duty of care. The clubs and involvement of the carers means the onus of responsibility on the staff is shifted, allowing for the informality that is so welcomed by all who responded.

Our current dementia practice models of home, day care, respite and long-term care, all serve to separate the couple for periods of time and shift the responsibility for caring in favour of the service provider for the periods of time the person with dementia is under the care of the ASI.

This separation and shift of responsibility adds greatly to the burden of documentation, accountability and legal responsibilities placed on service providers. Without the separation of couples, the primary responsibility remains with the carer but the carer is supported by the club/group, of which they are a member. It is important for the ASI to consider if social clubs enable carers to care longer by supporting their responsibilities, as opposed to traditional models that ask them to abdicate their responsibilities for short periods of time?

Questions need to be raised about which response works best from a policy and practice point of view, or do they have mutually exclusive benefits? Much of the literature around respite is inconclusive as to the direct benefits to the carer. In fact, much of the literature is based on whether the respite service benefits the carer, not the person with dementia. The key focus on the caregiver's break from caring, is paradoxically where respite programmes may fall down in terms of their perceived benefits, as carers want the focus to remain on the person so they receive a quality respite service. A theme consistent across all the literature was that the quality of care that the person received was a strong determinant of whether respite was accepted and

utilised. Therefore the separation does not always give the ‘break’ that one would assume as the carer has to prepare the person for their home/day care experience, may continue to worry about the person with dementia’s well-being whilst there, and has to prepare for their return and any possible fall out from the routine (Upton & Reed, 2005; Shanley, 2006).

More questions need to be asked about whether the social clubs can address the need for the carer to have a ‘break’ but still be in the company of their loved one, just with less responsibility for a period of time. Or as pointed out earlier, do all these models work in tandem, and benefit the person with dementia and the carer at different times and in different ways?

There are broader social policy implications too. The traditional approach of providing services to the person with dementia needs to be critically analysed. In addition, the policy approach of providing services ‘to’ as opposed to in ‘conjunction with’ the person needs to be debated, particularly in the field of dementia care. Giving people affected by dementia a genuine voice in relation to what services they need and want should be reflected in the policy approach to service provision. In addition, social policy needs to re-examine the current models of provision as well as research and identify new models of care that can support the concept of couplehood.

4.3 Recommendations for the Future

The social club model is undoubtedly an effective intervention with capacity to impact on a number of levels. There is clearly a place for the model to co-exist with existing ASI services or indeed it can stand alone. There is also a place for other stakeholders in dementia care, be they service providers, policy makers or other voluntary agencies to consider the findings of this study when developing strategies for people with dementia.

Key Recommendations

- The adoption of the Social Club Model should be considered across all regions in ASI to augment existing services and meet social needs of client and carer
- Additional resources must be identified and allocated in service planning to ensure that the Social Club Model's long term viability and sustainability are secured.
- Key staff in the regions must be supported and appropriately trained in the philosophy of the Social Club Model - which should include an educative process in group, counselling and facilitation skills.
- Consideration of the couple and their couplehood in all aspects of service and support delivery needs to occur to meet their need of being socially supported together.
- The findings of this research should be shared with key health and social care professionals in dementia care through dissemination of this report, presentations at conferences etc.
- The report should be disseminated to policy makers in order to influence and augment new models in dementia care.

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Appendix A

Guidelines for Setting up a Social Club

INTRODUCTION

The following guidelines have been developed to assist ASI staff in setting up a social club. They are based on the experience of staff that run the social clubs, the experience of members who have participated in them and ASI research on their development. These guidelines are intended as an initial attempt to support the development of social clubs regionally and will be reviewed as the ASI learns more about the model in practice.

What ultimately makes a successful club is that it is flexible to meets the needs of the members, it is social in nature and it nurtures and supports the ‘couple’ and their relationship. We know from research that the following are key to the success of social clubs:

- The relaxed, informal nature of the clubs
- The members’ active involvement in the running of their own club
- Outings and social occasions

WHAT IS A SOCIAL CLUB?

Essentially the social club is a gathering of people with dementia and their carers (usually the spouse but not exclusively) who come together in a social setting to support each other, share experiences and enjoy each other’s company. The club is facilitated by staff that have the necessary range of skills and empathy to support the members.

The social club does not use any formal therapeutic, counselling or rehabilitative model. It is not a service (in the classic sense) and its

structure is not hierarchical. It is 'owned' by the members, who in turn have a full say in what membership entails. It is an entirely flat structure.

The club is a safe and secure place for the members to attend. It is an opportunity for members to share information, coping strategies as well as build friendships with each other. The emphasis is on the social and fun elements in a fully supported, safe environment.

GETTING STARTED

Venue:

There are a few basic elements that need to be in place to enable the establishment of a social club. The first one is a suitable venue. It needs to be in an accessible location, preferably with parking facilities. The venue itself needs to have a room that can be dedicated to the social club activity exclusively, which should be comfortable and large enough to accommodate the group. It should have tea and coffee making facilities as well as bathroom facilities. The experience to date shows that locally based church/community centres are very suitable venues and most people identify readily with them. It is preferable to try to avoid clinical settings as the club is to be perceived as social in nature.

Timing of the Club:

Generally the clubs meet once a week on a weekday. The club meets for about two hours, mornings or afternoons. When the group goes on an outing, there is more time involved - up to half a day or more in some cases. Keeping to the same venue and time is important to provide regularity for the members. It is important to be mindful of the timing of other ASI or non-ASI day care services in the locality, as these may impact on the numbers attending the group.

Transport:

Transport is essential if the club is planning an outing. The local ASI day centre buses may be in a position to support the club with their transport requirements. However this can be limited by time and availability.

Funding:

You will need resources to pay for the room rental and the provision of refreshments.

Size of the Group:

There are no strict limitations on the maximum number of members who can attend. However, it is important not to have the group too large in order to keep the intimacy and a sharing environment and to facilitate the social skills of the person with dementia. You probably need a minimum of four to get the club going but a larger number is needed to keep it sustainable in the long term. It is good practice to maintain a 1:5 staff-membership ratio.

The Staff:

The clubs require staff member(s) to act as facilitators. Staff play several roles in the club - welcoming members, helping with tea/coffee, providing information, cultivating friendships, creating a warm, welcoming atmosphere, helping with personal care and organising activities/outings.

Apart from basic care and facilitation skills, staff need to

- Have listening and empathy skills
- Offer friendliness and warmth
- Show respect and dignity
- Understand the philosophy of the club
- Facilitate decision-making in the group
- Commit to working with the group for an extended period of time

Currently, the role of facilitator has been filled by ASI home care staff who have completed dementia-specific care training and who have the relevant experience.

The Members:

Membership is drawn from the local community. The practice to date indicates that the Home Care Co-ordinator in the area is well placed to identify and make contact with potential members. Word of mouth through the support groups and other ASI services is also a good place to start to identify members.

Membership is open with the only entry criterion being that one person in the couple has a diagnosis of dementia. Typically, it is a very suitable activity for people in the early stages of their dementia. There are no exit criteria (at present) for members. Those who have left have moved on to other services, left voluntarily or passed away.

It is important that there are core members in the group - i.e. that there is a number of people who are committed to attending regularly to enable a rapport/relationship to be built between the members themselves and the members and the staff.

Membership is entirely voluntary and no-one should feel compelled or obliged to attend.

Format of the Club:

Each club differs and the format for the club varies. What goes on in the club is led by the members. Checking in with the members is essential. Some of the following elements may happen:

Small group discussion/general conversation
Large group discussion/general conversation
Activities (e.g. exercise, playing music)
Cup of tea/coffee
Outings to local places of interest

Basic Rules:

If there are rules to be set, then these are negotiated and agreed by the group. The rules should include that each member is respected and made to feel an equal part of the group and that each member has a chance to speak if they wish.

Sustaining the Group:

The needs of the group will evolve over time and members will leave and new members will join. The need to continually build relationships among club members will be on-going within the group. It is a good idea to regularly review how the group is working. Consider checking in with the members that they are happy with the venue, day and time of the meetings; that they feel welcome and that they have an opportunity to say what they wish; how the club can be improved; topics for discussion; ideas for activities.

FEEDBACK

Your comments on these guidelines and feedback on how useful they were are welcomed. You can give your feedback or get more information on Social Clubs by contacting Catherine Keogh, Care Practice Coordinator on 01-2846616 or 086-3826395. You can also e-mail Ckeogh@alzheimer.ie

Appendix B



Staff

1. Which social club are you involved with? (please circle)

Bray

Athy

Rathfarnham

2. What is your primary role in the social club?

3. How long have you been involved in the social club?

4. Do you have experience working in other care settings? Yes No

If Yes, please circle which

Home Care

Day Care

Support Groups

Respite

5. How is the social club different to these other settings?

6. Is the way of working when involved in the social clubs different to other settings, and if so, how is it different?

The Club Specifics

7. How many people attend the club per week?

Clients _____ Carers _____

8. What is the ratio of staff/volunteers to clients?

9. What do you think is the optimum number of people to attend a club?

10. How are the trips and activities decided?

11. What are the days and times of the social club?

12. *Is there a cost to the client?*

If so, how much?

Set-up

13. How did the social club begin?

14. What requirements need to be in place for a social club to be successful?

15. If you were to set up a social club from the beginning.....

What would you definitely need?

16. What would you change/do differently?

Implementation

17. What are the factors that keep the social club going?

18. What kind of difficulties have you encountered in the day to day organisation of the social clubs?

19. How have you overcome these difficulties?

20. Have clients left the social club?

If so, do you know why?

21. How much do you think it costs to run the social club each week?

22. Do you think this is good value for money?

Best Practice

23. What are the benefits, in your opinion, of the social clubs?

24. What needs is the social club meeting, in your opinion?

25. Do you think these needs are being met in other types of services?

26. What would your recommendations be for the future of the 'social clubs' i.e. think about how you would like them to develop.

*Thank you for completing the questionnaire
and sharing your opinions.*

Appendix C



Which club do you attend? (please circle)	
Bray	Rathfarnham Athy
Who completed this questionnaire? (please circle)	
Carer	Person with dementia Both
1. How did you hear about the social club?	
2. How long have you been coming to the social club?	
3. Do you avail of any other clubs/services (please tick all that apply)	
ASI Services	Non-ASI Services
Home Care <input type="checkbox"/>	Home Help <input type="checkbox"/>
Day Care <input type="checkbox"/>	Day Care <input type="checkbox"/>
Support Groups <input type="checkbox"/>	Support Groups <input type="checkbox"/>
Respite <input type="checkbox"/>	Local Clubs <input type="checkbox"/>
Helpline <input type="checkbox"/>	Citizens Information Centres <input type="checkbox"/>
Other _____	Other _____

4. What do you enjoy about the social club?

5. What needs does it meet for you?

6. Are these needs met elsewhere in the other places/services you avail of?

7. How are the trips/activities of the social club decided?

8. Do you have a say in how the social club runs?

9. Is there anything you don't enjoy about the social club?

10. What basic requirements do you think need to be in place for a social club to be successful?

11. In the ideal world, with unlimited resources, what would you like to see in place for the social clubs?

12. Have you any other comments on your experience of the social club?

Thank you for completing this survey. Your views are important to us and will help shape the development of the social clubs.

Appendix D

Social Club Research

Interview Guide for Key Stakeholders

1. ORIGINS OF THE SOCIAL CLUBS

- 1.1 Explain the origins of the social club/the thinking behind their emergence/the impetus for their set up/where the idea came from?
- 1.2 Philosophy behind the Club - what is it? Why?
- 1.3 What is needed to set up a club?

2. THE MODEL TO DATE

- 2.1 What has worked and why?
- 2.2 What has not worked and why?
- 2.3 Key factors contributing to their success?
- 2.4 What previously unmet needs are addressed?
- 2.5 What are the key benefits of the clubs?
- 2.6 Is there anything about the clubs that you would like to see discontinue or that should definitely continue?
- 2.7 Where do you see the clubs fitting in with the other ASI services; broader context; continuum of services or not?
- 2.8 What are the entry and exit criteria for participants? Should these be formalised?

3. THE MODEL IN THE FUTURE

- 3.1 What is your vision for the future development of the clubs?
- 3.2 What needs to be put in place to make this happen?
- 3.3 What would you definitely like to see or not like to see happening into the future?



THE ALZHEIMER
SOCIETY *of* IRELAND

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