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Care Networks Project
Growing and Maintaining Social Networks for Older People

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The researchers warn Aboriginal and Torres Strait Islander people that this publication may contain images of people who are deceased. We do not wish to upset or cause distress to living relatives and community members.

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# Table of Contents

**The CARE Networks Research Project at a Glance ................................................................. 1**

**Background to the Project .................................................................................................... 7**

- Literature review ..................................................................................................................... 7
- The Research Design ............................................................................................................... 9
- Recruitment and sampling ..................................................................................................... 10
- Method ..................................................................................................................................... 11
- Data Analysis .......................................................................................................................... 12
- Ethical considerations ............................................................................................................ 13

**Introducing the Sites and Participants ..................................................................................... 13**

**Findings and Discussion .......................................................................................................... 14**

1. Forming Connections ............................................................................................................. 15
2. Enablers of social connections ............................................................................................... 20
3. Building Bridges .................................................................................................................... 26
4. Barriers to network development ......................................................................................... 28
5. Health & Wellbeing ............................................................................................................... 34

**Methodological Findings ........................................................................................................ 36**

**Looking Ahead: Recommendations and Conclusions ............................................................. 37**

**References ............................................................................................................................... 40**

**Appendices ............................................................................................................................. 43**
### Brief summary

What benefits are there in caring for older people? Are older people engaged in their communities, if so how? How do you conduct inclusive research across cultural groups and with people who have high support needs?

This report documents the findings of an innovative qualitative research project which investigated the nature of social networks that develop through caring for frail older people. The research was conducted by a team from Social Justice Social Change Research at the University of Western Sydney (UWS), lead by Dr Debbie Horsfall. It was funded by Ageing, Disability & Home Care for the period June 2009-June 2010.

One hundred and fifty-eight older people, carers, volunteers and HACC staff were asked to describe social connections that have developed, or are maintained, due to the receipt of HACC funded interventions. A technique called Photovoice combined with group interviewing was used to help participants identify what is significant to them in giving or receiving care.

The collective and individual benefits of participation in, and engagement with, the local community or society in general are well accepted and range from increased health and well-being to decreased crime rates. Indeed, social relationships are as vital to our well-being as food, shelter and cleanliness. Social capital is the most commonly used term to reflect these collective benefits and social networks are a key concept in this literature. However, when caring is linked to social capital it is generally assumed the relationship goes one way: that social capital is a resource to be used. Moving away from this deficit approach we asked the question: **Does caring for older people help to grow new social networks and new forms of social capital?**

We found strong evidence that the provision of care does indeed develop and maintain social networks for the older person, their carer, staff and volunteers. These networks are developed through, for example: shared activities; receiving the right help at the right time in the right way; and, shared culture, history or circumstances. This report further documents many examples of how these networks are developed. We also found that there are a number of barriers to network development. In particular there was evidence that gendered expectations of caring and the expectation to ‘remain independent’ and not ‘become a burden’, worked against people forming new relationships or even maintaining existing ones. The circumstantial barriers were: frailty and disability; the demands of caring; individual mobility; and, staff turnover. Overall, this research found clear evidence that caring for older people has collective benefits for communities, beyond the benefits for the older person and caregivers. However, maintaining and growing social networks requires appropriate resourcing and an understanding of caring which goes beyond the mere provision of service types.

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158 older people, carers, volunteers and HACC staff spoke to the research team about support and friendship connections developed through their participation in elder care.
The Care Networks Research Project at a glance

Introduction

Ageing is often associated with a reduced ability to engage in the community both for the older person and, often, for their carers. The result of this reduced ability can be social isolation and exclusion which is a cause for concern. There is however, growing evidence of the individual and collective benefits of participation in the local community and society in general, especially in the area of health and well-being and the associated impact on mortality and morbidity.

This report draws from social capital literature to frame an understanding of the collective benefits derived from caring for older frail people. Putnam (1993, p.169) defines social capital as those “features of social organisation such as trust, norms, and networks that can improve the efficiency of society by facilitating coordinated action”. We began with the view that caring for older people might contribute to, rather than drain, social capital. This approach is opposite to the more common assumption that social capital is a resource that can be used to provide care. Our approach sought to provide a significant contribution to the field of elder care, policy development and service delivery as we were responding to a lack of research that positions elder care as having benefits for the broader population.

Similarly, there is little research on the positive aspects of caring, and how individuals and their social networks might build community and social capital. In this research we focused on the social networks of older people and their carers receiving HACC funded Home Care and Centre Based Care (CBDC) by collecting and analysing qualitative data about current contributions to social capital, social networks and communities of people who are aged.

Formal research objective

To investigate the active engagement of older people in the community and make recommendations for strengthening the social networks of older people and their carers.

Aims of the Research

The ultimate goal of the research was to improve the status of caring through conceptualising caring as, possibly, contributing to growing community, not just draining resources. We sought to identify, explore and provide empirical evidence of the ways in which caring networks can contribute to the growth of social capital. Importantly, the research team wanted to achieve these aims by speaking directly with care recipients and their carers and to give their voices, stories and experiences a central place in the research. In other words, we wanted to know what the people involved thought about these issues.

As such our research questions were:

- What kinds of social and support networks do older people living at home engage with?
- How active are older people in maintaining these networks?
• Does caring for older people still living at home promote significant new social networks?

• Does caring for frail older people generate new forms of social capital?

Research Design/Methodology
The research team used an emergent design which was adapted to recruit older people, their carers, aged care staff and volunteers in natural settings of care. These settings of care included HACC funded day centres and people’s homes. A creative qualitative approach employing a technique called Photovoice, combined with group and individual interviewing, was employed. The research was designed in view that ageing, and caring for someone as they age, is often an emotionally charged and complex experience. As such methods were used that enabled the research participants to choose their level of participation when speaking of their experiences about formal and informal care networks. Participants were given cameras and asked to record the significant care and support activities they engage in. The visual data (photos) were then discussed and analysed by participants in a series of in depth interviews and focus groups. The research team conducted a thematic analysis of the recorded data and identified: how social connections develop, what enables connections to be made and maintained, and, barriers to the growth of networks.

Research Participants/Sample
The research team interviewed 158 older people, their unpaid carers, workers and volunteers living in the Nepean, Blue Mountains, (inner) Central Western NSW and Inner Western Sydney areas in order to learn about social networks that develop through elder care work. These participants were recruited from two sample populations:

1. Clients, carers, staff and volunteers from 9 HACC funded CBDC programs (128 people).

2. Older people and their carers who receive HACC funded in-home domestic assistance and personal care, HACC staff and volunteers (30 people).

Key Findings
Overall, we found that caring does not need to be a drain on social capital nor does it need to be an isolating experience for either the carer or the person being cared for. Rather, caring can contribute to social capital. Caring for the frail aged must be one of the toughest situations to manage in terms of growing social capital but people manage it. When caring generates social capital, it no longer just addresses a private need but potentially contributes to a public good, a resource that can be used by the network or community members to address other community needs. Further it models both the practice of caring and the caring society.

Proposing a toast, ‘Happy Days’.
After collecting the data in natural settings of care and transcribing interview and focus group discussions, the research team analysed the data using a thematic approach guided by key concepts in the social capital literature. Five core categories emerged in this process to be discussed in this report. These are:

1. Forming connections
2. Enablers of Social connections
3. Building Bridges
4. Barriers to social networks development
5. Health and well-being outcomes

Forming Connections is introductory in describing the ways social and caring connections are formed within and beyond CBDC and in-home care environments. Here we found evidence in both samples of connections being facilitated and maintained by the receipt of a service. Connections were formed and maintained through: shared activities; information sharing; providing community transport and access; referrals; building relationships with other community organisations; receiving the right help at the right time; and, supporting friends and family. Additionally connections were formed as a result of providing care whether this was the older people themselves caring for their friends and family or volunteers, staff and carers forming multiple connections across roles. A particularly strong finding here being that the act of volunteering can enable strong and multiple social connections to be made.

Enablers of Social Connections provides detail of things that contribute to the growth or maintenance of social networks. We found that a continuum of ‘enablers’ existed across the two samples, from personalised care to standardised service. Enablers included: a personalised quality to the provision of care; shared culture, history or circumstances; trust; acceptance; and, catering for fears and vulnerabilities. We found that services which focussed on ‘care as service provision’ did not enable social connections as well as services which focussed on ‘care as relationship building’.

Building Bridges gives examples of what builds connections between people, services and local community. All of the CBDC coordinators made connections into their community as part of other jobs. Some centres also mentored making vital links between clients, carers, the local community and other services. This mentoring approach is, we believe, more sustainable. This category was the smallest of our findings which suggests it is not seen as a priority for most of our participants.

The fourth category Barriers to Network Development details things that hindered the maintenance or development of social networks across the samples. These barriers emerged from social conventions/social norms, as well as individual circumstances. There was evidence in this research that the gendered expectations of caring and the expectation to ‘remain independent’ and not ‘become a burden’, often worked against people forming new relationships or even maintaining existing ones. Often with the result that people did not ask for help when they needed it, or they
relied on a very small number of people to meet their needs. The circumstantial barriers were: frailty and disability; the demands of caring; individual mobility; and, staff turnover. Many of these barriers interconnect and compound the effects.

In the final section, the health benefits of being involved regularly in CBDC are described. This is not a surprising finding as the health and well being effects of being part of a community and having social networks is well documented. We found that CBDC are places that create, nurture and sustain important connections for people. Many of the centres we visited were lively places full of fun and laughter. This challenges the social assumption that places full of elderly people are sad and lonely.

**Findings on method.** We include this as to the best of our knowledge the methodology employed is innovative in the field of elder care and social network analysis. The creative qualitative approach enabled us to gather in depth information from older people, their carers, staff and volunteers. We were especially pleased to find that the combination of Photovoice and group interviews was inclusive of many people across cultures and service types and enabled us to hear the voices of the frail aged. We also found that in order to gather rich and meaningful information about social networks, it was important to use a social networking approach to the research.
Summary of Recommendations

1. An ongoing funding mechanism to increase the capacity of CBDC programs to continue their social networks facilitation role. CBDC programs are clearly beneficial for maintaining and growing the social networks of older people, volunteers and informal carers.

2. Funding providers and policy makers to further endorse and strengthen the social networks building functions of in-home care work. The maintenance and development of older people’s social networks is as necessary to their wellbeing as food, cleanliness and activities. Formal carers and volunteers providing in-home care and domestic assistance play an important role in maintaining or growing the social networks of older people.

3. There is much scope for aged care workers and volunteers to teach/mentor older people and their carers in how to build social connections and in how to be self-advocates. Some older people and their carers are bewildered by ‘the system’ and would benefit from HACC-funded services mentoring them in self-advocacy skills.

4. Training and professional development opportunities where staff can learn about modelling social network formation could be increased. CBDC programs that are skilled in mentoring social connections can teach other CBDC programs in how to do this better. This research project revealed some best practice examples of services mentoring older people and their carers in establishing social and care connections.

5. We found some tension between providing a service, caring and the needs of clients – the most obvious being the meals on wheels volunteer who found a client sitting in the dark because she was unable to change the light bulb. In situations like this some paid carers and volunteers are unsure about whether to help the client or how to obtain the required help. Some helped in their own time at their own risk. Some clients relied on ‘private arrangements’ to meet their needs. At best masks unmet need and at worst could expose clients to exploitation. Although we appreciate that occupational health and safety regulations, duty of care, privacy legislation and risk management procedures have been developed to protect clients, staff and volunteers, we found that the risk is often just transferred from one to another. Care giving and social networking can be inhibited in these situations. In order to maintain a person centred approach and to ensure that service provision enhances care giving and social networking, we suggest that service providers and funding agencies include these concerns in regular review of systems, procedures and regulations to identify the optimal solutions.

6. This research project revealed that older people’s engagement with CBDC has a preventative function in terms of helping maintain social and communication skills. Insofar as this preventative

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1 These recommendations are discussed further on pages 39-40 of this report.
effect occurs, older people could be encouraged to participate in CBDC programs at an earlier stage of frailty.

7. Further research needs to be conducted into: the role of gender norms in elder social networking; the benefits of engaging in cultural-specific and gender-specific CBDC groups vs. mixed-cultural and mixed-gender groups to increase older people’s social networks; how the norm of ‘independence’ and ‘not being a burden’ works against growing and maintaining social networks in elder care.
Background to the Project

Literature review

- Are frail older people socially active?
Recent studies into the active social engagement of older Australians say that the majority of people aged 65 years and over participate in cultural, recreational and other social activities. However, it is also true that active participation in the community significantly declines with age. For example, only 41% of Australians aged 85 years and over had engaged socially outside the home in the previous 3 months, as compared to 72% of people aged 55-64 (AIHW 2007). Disability, frailty and associated losses of physical functioning are clearly associated with decreased levels of social engagement and increased social isolation (SPRC 2009; Hillier 2007). The significance of social isolation has prompted calls for innovative coordinated efforts to be put into promoting active participation in social networks by older people living in their own homes (SPRC, 2009).

- Socialising, support or care-giving?
The HACC program in NSW offers basic maintenance and support services to frail older people so that they can continue living in their own homes and thereby avoid or delay admission to long term residential care. HACC also funds, in whole or part, a range of community based support services that offer emotional and instrumental support to frail older people and their carers. However, given people are now living more years in poor health, or with longstanding illnesses, there has been considerable research and policy attention in Australia and overseas to the role of informal care for future sustainability of community care systems (AIHW 2004). When considering the role of informal social networks as a source of long term care, it is important to ask whether these networks have the resources to sustain the high levels of care required by older people with chronic health problems. Keating et al. (2003) argue it is valuable to make distinctions between social, support and care-giving networks when making judgments about the sustainability and efficacy of informal care work. This distinction is important insofar as these authors found that for each transition through this hierarchy, for example needing care-giving rather than support, people’s networks contract.

- Who is doing the care-giving?
The emphasis on frail older people as a ‘social burden’ neglects their contribution as providers of informal care. Older people provide emotional support to one another and provide opportunities to exchange information and problem solve. It is perhaps the case that over a third of informal care to people aged over 65 is provided by other elderly people (Arber & Ginn 1990), with older women being more likely than men to have developed a network of friends they can draw on for support (Keating et al. 2003).

The aged care workforce comprises three key segments: formal workers, informal carers, and volunteers. Formal carers in NSW provide services to the aged in their own homes as well as in other settings including nursing homes, other accommodation for the aged and in HACC funded...
community-based settings. The bulk of informal caring work is provided by co-resident carers, including spouses. For frail elderly couples, spouses are the most significant carers putting in greater hours and more personal forms of care (Keating et al. 2003). Eighty-three percent of older Australian carers are caring for a spouse (ABS 2008). However, the largest number of those receiving help live in separate households, and these are mainly parents or parents-in-law of their carers. Research has demonstrated that adult children care-givers provide less intensive assistance than do spouses, with this difference most pronounced among sons.

Communities differ markedly in the frequency and nature of support networks. Wenger (1992) found the highest levels of satisfaction among older people who had long-standing neighbours living nearby (in addition to supportive family and friends), which suggests a relationship between permanence of tenancy and stronger social networks.

- How is social capital linked to caring for the elderly?

When caring is linked to social capital it is generally assumed that social capital is a resource that can be used to support care work. For example Beaudoin and Tao (2008) examine the support that carers receive through on-line chat rooms and how this helps them deal with stress and depression. Jepsson-Grassman and Whittaker (2008) studied the support given to the frail and dying by their parishes and found that support was provided only when there was a personal relationship with the minister or inner core members of the church. In these analyses of caring the emphasis is on who a person can call on for help if needed.

Carroll et al. (1993) noted that the benefit of social support among elderly people is considerable and, conversely, that low social support is related to increased morbidity and mortality and slower recovery from illness. Social support and social interaction has obvious benefits. There is, however, danger in promoting the overly simplistic view ‘the more often older people get out, the better they are’. Institutionalised older people are coerced to engage in social recreational activities ‘for their own good’ despite there being little empirical support for the claim that all people benefit from engaging in social activity. Individuals vary considerably in the desire for social relationships, and in the benefits or costs they derive from social relationships (Gannon 1999:23).

There are a number of positive outcomes for the individual that can be identified for people who are active in the community. Leonard and Burns (2003) noted greater recognition, diversity of networks, and a stronger sense of personal agency for unpaid work which is in the public rather than the private sphere. Onyx and Warburton’s (2003) comprehensive review of the literature on social networks and healthy ageing over the past 20 years demonstrates that a strong link has been established between volunteering, social capital and maintenance of health and psychological well-being. Prospective studies of community populations have been particularly convincing, because these are able to demonstrate a causal pattern over time (eg. Oman, Thoresen & McMahon, 1999). These studies demonstrate fairly conclusively that social networks strongly predict reduced mortality among older age groups.

In Sweden, Sand (2000) noted that if the person being cared for cannot be left alone for long periods and there is little assistance, the carer can find her/himself socially isolated. Further, the situation may not be much better for the paid care workers. Ahnlund (2008) found that it was not uncommon for home care workers to feel bored and isolated left alone with clients who are unwilling or unable
to leave their homes. However for those who went out regularly there were good networks among neighbours, local shop-keepers and community nurses. Paid workers in institutions generally reported good relations amongst their fellow workers but relationships beyond the institution were limited for both the clients and themselves in their work role. At the most negative they were too busy to talk to the clients or each other and had not taken a client out for a walk in a long time.

Deficit based research continues to dominate research into social capital and elder care. However, Leonard, Johansson and Noonan (2009 under review) identified examples that show that caring does not need to be a drain on social capital nor does it need to be an isolating experience for either the carer or the person being cared for. These authors contend that caring can contribute to social capital. The present research aims to identify and explore ways in which elder care can contribute to the growth of social capital in addition to identifying barriers to social network growth in elder care.

The Research Design

Ageing, and supporting someone as they age, can be an emotionally charged experience of complex and competing emotions. As stated above, literature about caring has emphasised burden, stress and dependency. This is what we are used to. They have become taken-for granted assumptions about ‘the way it is’ for older people and their carers. Talking, and thinking, about ageing and caring as a process which increases social networks and contributes to social capital is not, therefore, going to be easy. Speaking about things in new ways requires new ways of asking questions and thinking about things. Furthermore, as researchers we need to be particularly sensitive when asking people to talk about emotional issues which could leave them feeling vulnerable and exposed. Methods need to be employed which enable the participants to remain in control as much as possible, and to hopefully receive some benefit as a result of the researching process (see Horsfall & Titchen 2009).

Creative research methods have enabled participants to organise their thoughts and feelings first and then elaborate verbally on their ideas, often to an extent that they could not have done if they had not first represented their ideas visually (Davidson, 2004; Horsfall & Welsby, 2007). Creative methods can also enable people to notice and then speak about what has now become familiar or taken for granted (Halen-Faber & Diamond, 2002). Adopting a creative approach in this project was deemed important as social networks are often invisible, not talked about, or are seen as an unremarkable part of people’s everyday lives.

This project used a qualitative approach informed by Photovoice and focus group interviews to enable identification of caring and social networks from the viewpoint of older people and their carers. Photography is a means by which the unspoken or difficult to speak about can be made concrete. Developed by Caroline Wang (Wang, 2006), the technique Photovoice elevates the participant to the status of expert in the analysis of their own lives instead of merely making their lives available for analysis by others. In this method visual imagery is used to enable people to think critically (Freire, 1970), in this case about their social networks and relationships. In Australia this method has already been used successfully as a research and community development tool with people who have a disability, people who are homeless, exploring indigenous sexual health issues, with culturally and linguistically diverse groups and by the Nature Conservation Council of NSW (see Webb, 2004 & NSW Department of Health, 2007).
In the current project, formal care staff, volunteers, and clients at CBDC programs were given cameras and asked to take photographs of care and social activities that were important to them. Some clients and carers receiving in-home care also took photos of significant caring activities. Following the development of these photographs people were given the opportunity to discuss the photos in group interviews. In these interviews photographs sometimes assisted as a ‘neutral’ third party between researcher and participants insofar that rapport could be established more quickly around photo discussion.

**Recruitment and sampling²**

Recruiting elderly people and their carers to participate meaningfully in research projects poses some difficulties (Higgins 1998). Challenges encountered in our project included: difficulty recruiting elderly people and their carers through the Home Care Services (possibly due to the busy routines of personal and domestic care staff); working with the routines of CBDC (these groups often meet once weekly and many did not meet over the Dec-January period); lengthy time to collect data (using a photo-elicitation technique requiring several visits to Centres); timing of approach (conducting research in natural settings including people’s homes required us to work around caring events or other activities). During the recruitment phase, some CBDC managers declined on the grounds their clients, particularly those with dementia, would not be capable of participating. Perhaps these coordinators were overly concerned with ‘competence’ as being the goal of participation. Conversely, those coordinators who accepted the project invitation acknowledged older people will contribute in different ways. These centre coordinators gave the research team instruction in how to meaningfully engage frail clients and clients with dementia. Here, participation in the project itself was seen as a goal of engagement.

Determining who the appropriate participants were for this study was guided by the question ‘what samples can best provide information-rich and comparative stories about social networks that develop through caring work?’ Accordingly, research participants were recruited from two distinct sample populations. The first sample population included 128 older people, carers, staff and volunteers involved in HACC funded CBDC. The second sample included 30 people involved with

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² Our original research design included HOMEHospice Inc. inviting their clients to participate in this study. This did not eventuate. However, two of the research team are currently completing research which has included HOMEHospice clients and we are happy to provide ADHC with a copy of the final report.
HACC funded in-home care services networks, comprising elderly people, their carers, staff and volunteers providing formal care.

The sampling strategy achieved recruitment from a mix of semi-rural and metropolitan areas, and areas where there is cultural and ethnic diversity. A criterion for the selection of centres was guided by demographic regions chosen by ADHC which were the Nepean (Penrith, Hawkesbury and Blue Mountains) and Central West regions. However, three CBDC groups were recruited from outside these regions: two from Sydney’s inner west and one from Western Sydney.

The research team encountered more difficulty recruiting the second sample which was older people and their carers receiving HACC funded in-home care (otherwise not attending CBDC). The initial attempt to recruit this sample via the Home Care Services (HCS) had limited success. We had more success recruiting from NGO’s delivering HACC funded services in the Nepean region. These organisations made contact with clients or volunteers directly to ask if they would like to participate in our study. Selection of clients or volunteers by these organisations and HCS staff appeared to be based on the kind of relationship the service had with the person, the length of time the organisation has been involved with the person, and the health of the client. In this sample, 30 clients their carers, volunteers and formal care providers were interviewed at home representing 17 networks.

Method
Researching in natural settings, or going to where your participants are, requires meticulous and sensitive planning. We consider that it is worth the effort especially when asking people to talk of their experiences and stories. Speaking with people in their own environments, where they feel comfortable or where the activity which you wish to speak about takes place can prompt them to speak of things they may not have thought of. This approach to doing research also seeks to address the power imbalance between the researchers and participants. This is important if we wish to hear about things from people’s point of view.

Setting up the fieldwork therefore took several months. In the first sample the research team made 3 or 4 visits to each CBDC group, initially to meet coordinators and get consent for accessing the CBDC group, then generating enthusiasm and awareness about the project amongst key staff. A formal information session at each centre was facilitated with a professional photographer to explain the project, get consent and explain how to take photos using the disposable cameras provided. Six weeks later, members of the research team returned with the developed photos, a cake to share, and to conduct group interviews. A Cantonese speaking research assistant was employed to conduct group interviews at the Chinese CBDC. All people attending the centre were invited to attend: carers, clients, staff and volunteers. In some of the smaller centres everyone did

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3 We had hoped to also develop network maps and discuss alternative models of caring, such as the Swedish cooperative model of elder care and the HOMEHospice model of community mentoring, as part of the focus group and interview process. Unfortunately this proved to be too ambitious a method for our current sample. Groups were too large for network mapping and respondents were not interested in other models.
participate in the focus groups, while at some of the larger centres, or those whose clients included people who were particularly frail or who had dementia, participation was more selective. Volunteers and staff also attended the groups although this was often sporadic as they took time out of their busy schedules. When key staff did not attend the focus groups, the researchers made sure they spoke with staff via an informal interview before they left. At all centres the cameras were used by clients, carers, staff and volunteers resulting in a wide variety of images.

The focus groups began with people looking at the photos that had been taken. People were interested in what had been taken and lively, at times chaotic, discussion flowed from this activity. Participants were then asked to select one or two photos which particularly stood out for them, and to give the photo/s a title. The focus group discussion began with people explaining their photos and the title they had given. This then led to in-depth discussion of significant caring activities (see appendix for schedule of questions asked in sample 1).

In the second sample; which comprised older people receiving HACC funded in-home care and their carers (formal and informal), two meetings sufficed to explain the project, organise photo taking and conduct interviews. These meetings had been organised by the coordinator of the NGO delivering the service or the individual HCS worker providing care. We are grateful that these people had taken the time to explain the project and invite participants into the project. Some participants in this sample chose not to take photos. For those who did take photos, some declined to give them a title. The untitled photos in this report then, are from this sample. In these situations the researcher arrived at the organised time to visit the participant and members of their care network who were available on the day. An informal interview took place, often over cups of tea, about the nature of the care-giving or care-receiving role and how this role might contribute to growing social connections (see appendix for schedule of questions asked in sample 2).

Across both samples participants were engaged in interviews via the photographs which often stimulated laughter, discussion and reflection about social and caring activities they have enjoyed. Some fantastic photos were taken by participants and it is our view that the use of photos in this report makes the discussion more compelling.

**Data Analysis**

The first level of analysis took place in the interviews where participants’ were asked to give meaning to their photographs or the activities and tasks they spoke of. This was in order to gain the stories of participants and to understand what was important to them, in terms of caring and the generation of social capital.

With participants’ consent, interviews were audio recorded and later transcribed. The research team initially coded this data according to the kinds of connecting activity observed. In doing this we were guided by key concepts in the social capital literature. Practices of engagement, trust or behaviours that seemed social norms-based were coded. A second round of analysis was undertaken to identify trends which enable the growth or maintenance of social connections. Conversely, things that appear to inhibit forming social connections in elder care were also identified. In this report these practices and trends are organised into 5 core categories: Forming Connections; Enablers of Social
Connections; Building Bridges; Barriers to Social Networks Development; and, Health and Well-being Outcomes. Each category contains relevant findings interspersed with discussion.

Ethical considerations
There were several important ethical considerations in this project. First, it was important that participants understood the project rationale and what the research team intended to do with the photographs and other information collected. We thought it was important to communicate to centre staff that the project celebrates the valuable caring work they do. Second, it was important to get people’s consent to be involved. Centre managers and all participants signed an information sheet that provided details about the project, the use of photography and what would be done with data collected (see Appendix for samples of information sheets and consent forms). For those participants who could not sign due to illness or frailty, effort was taken to get the consent from their carer. In the event that consent was not given, no data collected involving this person was used. All of the photographs in this report and in other publications by members of the research team are used with the permission of participants. The project received UWS ethics clearance prior to commencement.

Introducing the Sites and Participants

- **Introducing the CBDC sites**

  **Gilgai Day Care** is a committed centre with 22 years of expertise in community building, welcoming the participation of older Aboriginal and non-Aboriginal older people and their carers. Clients usually come to the Centre more than one day a week to meet together, share a meal, play games including Bingo, and go on bus trips. Gilgai provides a comprehensive service that includes carer support, aged care packages, day centre programs and disability family support.

  **Riverwood Men’s Group** is a social group for older men run by three staff and two volunteers. The 15 men attending use the community bus to get to the group once a week, where they participate in discussion and storytelling, sharing meals, exercise and going on outings. The Riverwood/Canterbury Aged and Disability Support Service also provide assistance with shopping.

  The **Chinese (Cantonese and Mandarin) Day Care** program also operates out of Riverwood/Canterbury Aged and Disability Support Service. The program is fortunate to have bi-lingual staff and volunteers working on a weekly basis. The Friday Cantonese Day Care group which participated in the project is a lively, happy group of approximately 30 older women and men who participate in gentle exercise, information sharing and going on outings.

  The **Warragamba/Silverdale Day Care** program is run each Thursday morning by Nepean Food Services. The older women are transported to the community based facility to participate in card playing, sharing meals including going out for lunch, and catching up with friends. A weekly shopping bus to Penrith also operates out of the Service.

  **Richmond CBDC** is a service of ANGLICARE Chesalon Aged Service, offering a respite service for elderly people with dementia who live in the Hawkesbury area. The centre operates Monday, Wednesday and Friday and transport is provided. Staff, who are assisted by a range of volunteers,
design activities as a means of accommodating different people’s abilities. Sometimes clients are taken on outings. Formal and informal carer support services are also provided through the Centre.

Winmalee CBDC is a small, social program for older people living with dementia also run by Chesalon ANGLICARE Aged Services. The CBDC offers respite to carers, some of whom attend the Winmalee Carers Group facilitated by the CBDC coordinator. Over 30 volunteers contribute to the program including musicians, artists and gardeners.

The Bathurst Seymour Centre runs a day care program for local frail aged people. The staff provide a supportive environment with the help of a range of volunteers. People attending the centre engage in activities of their choice including: cards and table games, crafts, music, reminiscence and oral history, outings, Holy Communion conducted by Catholic and Protestant clergy, gentle exercise and conversation.

The Nepean Migrant Access Service facilitates a number of CALD Day Care programs currently comprising two ethno-specific groups and two multicultural groups. The Tuesday group, which participated in this project, is a group of 15-20 older women and men from various cultural backgrounds. The group meet for morning tea and discussion followed by a lunch outing.

- **Introducing the in-home care sample**

We interviewed 30 people representing 17 different ‘care networks’. This sample included: older people receiving HACC funded personal care and domestic assistance, formal and informal carers, and volunteers involved with delivering meals on wheels. These people live in the Blue Mountains and Nepean. Most of the older people in this sample had significant frailty. The majority of older people we spoke to owned their own homes and were financially stable.

![Michael and Me](image)

**Findings and discussion**

The project findings are organised into five core categories, or sections. *Forming Connections*, the first section, is introductory in describing of the ways in which social and caring connections are formed or maintained through caring work.

The second section, *Enablers of Social Connections* provides detail of things that contribute to the growth or maintenance of social networks. Following this, practices of *Building Bridges* through eldercare networks are described. In the fourth section, *Barriers to Network Development*, issues
that hindered the maintenance or development of social networks are described. Barriers to social connection emerged from social conventions or social norms, in addition to individual circumstances. In the final section Health & Wellbeing Outcomes, the health benefits of being involved in CBDC networks are described. As we were interested in what participants had to say, both quotes from the data, photographs and relevant titles and captions are included to illustrate the findings.

In communicating the project findings all names used are pseudonyms.

1. Forming Connections

- How are connections made within CBDC programs?

We did not begin with a ‘clean slate’ approach in this research. Instead we recognised that there would be evidence of existing connections between people in centres. However, it is important to be able to document how people form connections within CBDC. Providing evidence of already existing practices can assist in strengthening these practices further. It is also one way of making visible and valuing what is often taken for granted, or seen as ‘common sense’. Clients, carers, staff and volunteers at CBDC form connections through shared activities like playing cards and games, music, and craft. Many moments of fun and laughter were observed when visiting centres and many participants chose photos in which people are enjoying playing together,

We come here to play cards, catch up with friends. Even though we might like to think it is not a competition… when you euchre someone, it is a bit of an accomplishment! (Client)4.

We always learn something new here. I enjoy the wide variety of activities we do here, such as dancing, singing, outings and bingo (Volunteer).

In some centres games and craft activities have been developed specifically to enhance the capacity for older people with special needs to engage,

We have started playing darts and indoor bowling as a way of including the men who find it difficult to communicate verbally (Volunteer).

At all centres, information sharing helped people to connect in addition to learning or skill benefits,

They have guest speakers who give us information we are not aware of which can help us care. It is really good. Coming here has been very helpful for me as well as for Nan (Carer of client attending CBDC).

We had suggested going to visit the nuclear plant… an interesting day. We can keep learning things (Client).

_____________________

4 All comments are direct quotes from participants and have not been edited by the researchers.
We come here for an information exchange…. we are free to speak here. Reading it on paper isn’t as good as meeting here and talking about it. Nowhere near as good. Human contact (Carer at Centre-based support group).

The valuable role of the bus in transporting elderly people to centres cannot be underestimated. Several clients spoke fondly of the bus driver or voiced their appreciation for the bus driver helping from their front door to the bus. A number of people spoke about the significant role the bus driver has in building and maintaining connections between the centre, clients and their carers,

*The bus driver talks to carers about little problems. She has a strong connection with some of the carers* (Volunteer).

We all love him like a son

Absolutely doing the bus run helps build contacts. I have very good bonds with most of the carers as I go around. Some of it is almost like a counselling opportunity. It’s one of the real pluses of the bus run that you get to meet all the carers on a daily basis like that (Bus driver).

*People get out into the community for bus trips. One thing people like doing is going to look at the new estates around town. They remember how it used to be and they can see the change. These outings help them to connect with where they live* (Worker).

I wouldn’t get there without the bus

Having a regular organised time to meet together was important for maintaining social connections at centres. Some clients and volunteers spoke about regular attendance at the centre over many years and how important the centre is for helping them ‘stay together’ with friends.
Building social connections beyond CBDC

Participants were asked to describe how connections might reach beyond or outside the CBDC program. In response to this question, several clients, carers and volunteers spoke about friendships made that reach beyond the centre,

_Sometimes the volunteers go to each other’s house and organise a lunch or an afternoon we have done this a few times. We bring our husbands too. Sometimes husbands are very good cooks!_ (Volunteer)

_Not many see each other outside of the group. But one couple have made good friends, they have been friends for 15 years. They do the shopping together, have lunch together_ (Coordinator).

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Another kind of connection reaching beyond the centre is with other support services,

_Oh they’ve been wonderful, like, I’ve had a few medical problems and they’ve come and taken me to the doctor in the bus. They organise cleaners and home care each week and usually my home carer will take me to the doctor. I didn’t know half of these things existed till I come here!_ (Client)

Connecting clients with other services sometimes occurs via staff making referrals. When a coordinator or staff member assumes responsibility for making these connections, questions might be asked about the sustainability of the connection. Will the connection remain after the staff member leaves the service? On other occasions these connections develop due to clients or staff mentoring, or modelling, to clients and their carers how to make connections. Learning from mentoring how to make and establish connections is perhaps more sustainable. Having transport to other services and organisations is pivotal for making and establishing connections.

Centres have various formal and informal connections with community organisations and churches,

_We get a lot from our local church, we’ve got a very good parish relationship out here with the Anglican church. Once a month, we take the clients down for a church service and communion and they provide lunch. We spend the day down there._ (Worker).
Once they start coming to the day centre we get invited to other community functions which then we take them to. So whether it’s NAIDOC, whether it’s Sorry Days, whether it’s other organisations out there; UWS, with TAFE, other Aboriginal organisations. We go to the Club, the Builders, Blacktown Workers, we go there (Coordinator).

On a few occasions, the connection volunteers and clients have at the CBDC seemed but one in a web of entangled social connections. In these examples of multiplex connections, having a shared history or shared cultural identity featured strongly,

I have lived in this area for 20 years and I began the Cantonese group at the centre ...every week we have meetings...bible study...do charity...we have to visit them, we have many, many things (Volunteer).

People here are involved in seniors, shopping trips ... and other outings. One of us will say I am going to blah and another will say “I’ll go too!” We catch up with friends. We hear about things through going to other things. They all mingle (Client, semi-rural CBDC).

- How do people receiving or providing in-home care build connections?

When we asked clients and carers receiving in-home care about what things assist them to be socially connected, the simple significance of receiving the right help was discussed as something that enables connection. For example, having the right medication or assistance for a condition, or being showered or fed contributes to an elderly person being well enough to connect with others,

Helping get the Vitalcall stuff done in case he fits and getting the guy from UnitingCare and that help. It’s been just wonderful to see (the elderly persons) world open up! (Carer/ friend).

If I didn’t have the help I wouldn’t be able to do very much at all! (Elderly client).

Several elderly clients we spoke to who receive HACC funded in-home domestic assistance have used their agency and relative wealth to organise other people to perform errands and support tasks. These are privately paid arrangements,

Cheryl is a private arrangement it suits me. Like tomorrow I have two appointments, Cheryl will take me and I will pay her for that. That arrangement begun through using cabs you get to
know the cab drivers. Cheryl’s husband was one of the taxi drivers. He couldn’t do me so he said Cheryl my wife could do you (HCS client).

A man comes with a van and he does the cleaning. That is a personal arrangement (HCS client).

Others draw on existing connections with friends and neighbours to help them get out and be active in the community,

Oh, I go to Bible Studies Fellowship too on Wednesdays. That’s down at the Salvation Army Hall. My friend Jill who used to live next door, she takes me down. She likes going as well (HCS client).

The worker is also good company

It can go unnoticed that elderly people who are receiving care are often actively caring for others (Arber & Ginn, 1990). A number of people we spoke to both in the centres and at home kept an eye on each other via phone calls, often suggesting activities, or checking if the person was OK. For example, one older woman we spoke to who receives in-home care rings a friend (who has dementia) weekly, in addition to regularly visiting a family member in a nursing home. Regularly supporting others helps to grow social connection,

I do visit my aunty in her nursing home. I get along with the people there, we have a laugh and a joke... yes it is like belonging to a community, I never thought about that. They know me... I have made some really nice friends. The cook, the cleaners, the Sisters (HCS Client).

A patterned observation across both samples was strong social connections being made through volunteering. Several volunteers in this study have developed multiplex connections, that is, they connect with clients in the home setting and when they see them in the community, in addition to making friendships with other volunteers outside the volunteering role. Doing volunteer work also can help with maintaining existing friendships,

I definitely get more out of it than the clients do, ‘cause all they get is a meal! I suppose I get a feeling of satisfaction I’ve done something, because I am retired and all that nonsense. I talk about (doing volunteering) at the pub on occasions with me mates (Volunteer).

Through doing meals on wheels I talk to more people than I would otherwise, I talk to my customers and with some of them we get on really well, my last customer or 2 on the round I stop to chat to for maybe a quarter hour because we get on well. It’s just like meeting people you like! I speak to them in the shops (Volunteer).

I’ve helped hang washing out at times...get to know them talk about grandchildren, just stop and have a chit chat. It’s very easy to see in a few minutes if they are ok (Volunteer).

Paid care workers can also form strong, trusting connections with clients. Home care workers in our sample had been caring for some clients over many years. In these stronger connections were two
examples of workers and clients negotiating a schedule that is flexible to meet both of their needs. Stronger connections involved regular mutual exchange between client and carer about family problems.

Other staff and clients have formed weaker connections. Here, chatting will happen but it is seen by the worker as ‘part of the job’ and less as mutual exchange,

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\text{I don’t do many cleanings, but half of it is having morning tea and chatting. It’s good for them. That’s just a part of my job. You know, just the talking…sometimes, some people you are the only person they see in a week (Home Care Service worker).}
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In both samples there was evidence then of connections for older people being facilitated by the receipt of a service; either attending CBDC or receiving in home care. Additionally connections were formed between volunteers, staff, carers, clients and other people and services in the local community. Social connections and relationships are the building blocks of social capital. Relationships were formed and grew as care was provided, of course the strength and nature of these relationships differed markedly. However, this does provide some evidence that the act of providing care does indeed serve to grow social capital. It could be argued that these connections were more varied in the CBDC settings, as would be expected with groups. Importantly, across both groups we also found that the provision of care was absolutely essential in helping people maintain existing connections and relationships. This maintenance role should not be underestimated and is seldom discussed in the literature on social capital. Growing and maintaining connections and relationships works against isolation and loneliness. Additionally, we found, particularly with volunteers, that new and lasting social relationships were formed as a result of volunteer work. Again this was most marked in the centre context.

2. Enablers of social connections

- A personal quality to the connection or care

The strength of connections is an important element of social capital and services varied in the degree to which they provided personalised care rather than a standardised service. The carers who were caring for husbands or mothers were the epitome of personalised care. They related to the whole person and tried to meet all their needs, sometimes at considerable personal cost. At the other end of the continuum were commercial services such as lawn mowing, a driver, a cleaner, and provision of assistive technologies such as shower rails. The care provided by HCS and CBDC programs varied along this continuum whereby more personalised care allowed for the development of a relationship between the care-worker and the care recipient.

At its most standardised the Home Care Service and Meals on Wheels (MoW) were similar to commercial services with strict limits on the help that is given,

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\text{They want their dinner. I’ve got their dinner. It is very satisfying (Volunteer, MoW).}
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\text{Well you see they are not allowed. They won’t do any shopping. There is a shopping centre over the road and it would be good if she could get me something (93 year old HCS client).}
\]
Some workers and volunteers emphasised the importance of keeping a distance but still helped with minor tasks,

You’d like to get more involved but you can’t …they become reliant on you then. You’ve got to be a bit careful. You do as much as you can….one lady …she had a light bulb blown in her kitchen and she couldn’t get anyone to replace and she’d been in the dark all night trying to cook, and I said OK (Volunteer, MoW).

However others emphasised that it was part of the job to check up on the clients,

I might only be there for 2 or 3 minutes but you can quickly sum up if they’re ok…there’s a lot of very lonely people out there, and even in 5 minutes I can make a cup of tea and just have a quick chit chat and that is often all they need…… and it’s good for me, my word, terrific! (Volunteer, MoW).

One HCS worker said it was misplaced to conceive the work like a commercial service and talked about the importance of compassion,

I’ve just had to train a few girls and they were doing the housework, and that’s what they thought it was, but it’s so much more than housework. I’ve found people dead, fallen out of bed and not been able to get anywhere. Now a normal house cleaner would go to the door, knock on the door and if there was no answer, go bewdy and go off. But we’re peering through windows and ring the phone. Some don’t see it this way, but they don’t last in the job that long if you don’t have that compassion.
Another volunteer talked about helping a couple get financial help for a service they needed,

I opened the door and they were crying as – they couldn’t afford it, they couldn’t afford the five dollars for a shower. So I rang Home Care, because I knew there were ways they could virtually get it for free, but it’s a lot of paperwork. But yeah, I wouldn’t leave them crying over it.

While there was a spread of quality of connection amongst people we spoke to we would like to draw attention to care-work as contracted service, or just providing a mosaic of functional services such as cleaning, shopping, washing. This does not seem to fit our understanding of care as normally understood nor as it is described in care theory. Perhaps the closest definition is in Tronto’s (1993) theory of care where “taking care of” involves “assuming some responsibility for the identified need and determining how to respond to it”(p. 106) But the word “responsibility” indicates that taking care of is far more than just providing services. "What is definitive about care... seems to be a perspective of taking the other’s needs as the starting point for what must be done” (Tronto 1993 page 105, our emphasis).

• Shared culture, history or circumstances
The sharing of a common bond due to common culture, history or circumstances was a salient enabler of social connections. Aboriginal CBDC staff and clients and the one Aboriginal HCS client we spoke to were clear about the importance of their shared cultural history and identity,

In another service would I do it as passionately, as connected, as spiritual? No, because who I am and who this place is and who they are ...connected to who we are in some way shape or form because we’re all Aboriginal (Coordinator).

That’s why we really get each other. People like me Jayne, Bruce who have all been taken away from family, there’s a real understanding that is not there with people who haven’t been through those things. A different kind of respect, understanding, sense of humour (Carer).
Those who had lived in the same rural area for many years shared a personal history and had strong bonds with those around them. Older people have been shown to draw meaning and security from the places in which they live and women in particular draw on existing social networks and neighbours to sustain their independence and social connection within their community (Wiles et al. 2009; Walker & Hillier 2007). This effect was observed in the smallest community we visited where the women had developed multiple connections over the years,

> Many volunteers are local. I think it’s from the personal connections more than anything. People like Lyn have been in this community for a few years (laughter)...All my life in other words (Volunteer).

> We have all known one another for years, back then we all knew each other. Our husbands worked together ...on the Water Board....Some of them have had close friendships for years but I think this is a unique community. It is small. The shared history. ... I have known Beryl for about 60. Jodie I knew about her even before I came here... I used to work with her sister (Client).

Conversely, when there was a weak cultural tie or short history of living in the area people spoke about the difficulty of connecting. One carer said, “we have only been here 7 years ...I think not being connected here is a hindrance to our getting support”. Another male HCS client who was isolated and lonely had moved to the area 14 years ago however still experienced being new to the area having previously lived in the same rural location since he was a child.

Having a shared experience of caring is perhaps just as powerful a point of connection as years of shared history,

> The other terrific thing is bonding with other people. We don’t have to go through the stages of getting to know people outside. You see, I go to Church, and I’ve been going to the local church for the last 12 years and I have a closer relationship with the people in this group than the people sitting down in church every week. Because here we’ve all got the same problems (Carer, Centre-based group).

As a corollary people who did not have the same shared experience were seen as difficult to connect with,

> What we say here we wouldn’t even say to our kids. Because they really don’t understand. Its only people who have dealt with it or been trained in it that understand (Carer).

> The bond, the trust, person to person.
The Cantonese group we spoke with did not talk about their shared culture but they all spoke in Cantonese and Mandarin and engaged in culturally specific activities such as Chinese dance and tai chi so clearly culture was a point of connection. Indeed many had limited English and would be quite isolated without the support of the group.

Those CBDC programs that did not have a point of connection such as a particular culture, history or experience needed to create a focus. When asked what helps people in the group get on, the coordinator of this group spoke about the value of information exchange,

> My view is it’s the information, once you give people information they have something to talk about (Coordinator).

- Trust

The basis of all social capital is trust. If we deem someone or a group of people as trustworthy, we implicitly mean that the probability that they will perform an action that is beneficial to us is high enough for us to consider engaging in some form of cooperation with them.

For example, one CBDC client had tried another program but had not continued because she did not feel safe at this other CBDC program. At the centre she now regularly attends she can trust the staff to act as she expects them to act. Conversely, distrust meant that a person avoided contact and assistance as in the male HCS client who avoids his neighbours, particularly the one who offered him lifts but drove “like a madman”.

Trust is important in maintaining and growing social connections and it emerged as a key enabler of connections in a number of guises. Across the two samples different experiences and practices of trust could be identified along a continuum from trusting in service reliability to having a deep trust in another person.

**Functional trust:**

At its most minimal trust features when a worker provides a needed service in a timely and competent way,

> Julie (the coordinator) is very capable. She gets us in and makes us do things. She goes around not just to one or two, she is dealing with all those girls and she keeps it going (Client, CBDC).

> I make sure there is someone at home to accept the food because if nobody answers the door, have they had a fall or something? (Volunteer, MoW)

In contrast, three home care clients talked about services that were not functional or reliable. In the case of the community bus, one elderly client did not want to “wait all day” to fit in with its schedule so she paid for taxis. Another was no longer able to use the bus because she needed help when she arrived at the shops which cost $30 per hour. The other concern was with a HCS worker who had been asked to do the shopping at a particular supermarket for cheaper groceries but ignored the clients request and went where she could collect “Fly Buys” points. The lack of a functional and reliable service limited the possibility of social connections due to lack of transport or demands on
very limited income. One HCS client felt she could not engage in activities beyond the home due to needing to wait for her worker to come,

By the time I wait for Penny to come... She is very good to me. I have to wait awhile because they have other clients. They fit you in around their other clients? Yes that’s right. I wait three quarters of an hour to have a shower (Home care client).

Physical safety:

Other clients expressed trust in staff that were looking out for their physical safety,

They’re watching out for me so they’re taking care of being beside me so if I stumble well they’re going to pick me up so I guess (Client, CBDC).

When I stand at the top of my porch, they come and help me into the bus. She says don’t you come down those steps by yourself! I will come back and get you! (Client, CBDC).

This consideration of people’s physical safety is pertinent especially for people who are becoming increasingly frail as they age.

Management of conflict:

Clients expressed trust in staff who managed the interactions in the CBDC so that conflict did not get out of hand. In some centres clients experienced a high level of safety,

Not all of us get along but I mean we just sit in here and don’t have to worry about it. The girls will work out all that, not us, and we don’t have to. They take care of all that (Client, CBDC).

Working toward safety in the group was reinforced by the coordinator of the men’s group who found a need to balance the right of each of the men to be there and express their opinions with the need to manage conflict. In contrast, a client at another centre expressed feeling the need to keep out of the way if there is a verbal fight; however, in the process she is not able to connect with the other clients,

I didn’t know anyone, everyone is new. I never had any problems if people fight I keep out of it. I keep to myself. I got no problems here.

- Acceptance

Clients and carers at several CBDC talked about the importance of not being judged or criticised which allowed them to relax, have fun, vent their feelings and ask for help when they need it,

You actually get a chance to vent your feelings without people judging (Carer at Centre-based group).

If you go down to the club and play euchre and make a mistake that’s not ok. Here we have a laugh, if you’re half asleep or something (Client).
Sometimes I feel closer here to family than what I do at home. I know I can ring here... and you can’t ring your family because they... you know ‘oh I’m going to get into trouble for that’. Whereas you can ring here and you don’t get... hmm criticise you for anything (Client, CBDC).

- Catering for fears and vulnerabilities

In the context of informal caring in the home, carers were very aware of the vulnerabilities of their loved ones. Several CBDC coordinators also talked about the need to be sensitive to client’s fears and disabilities. In both contexts, trust is created by adjusting to people’s needs,

She likes the security. When family comes to see Mum we all seem to congregate in her room, and we all lie on the bed, sit on the floor and have a cup of tea in her room. So that’s great... It’s nice and casual and safe (Carer).

If it wasn’t for Sue (coordinator) the way she is, there’s no way. I won’t have come here... she encouraged me so much and helped me out so much to be able to get out of my house. I hadn’t left the house for five years (Client, CBDC).

In almost all the CBDC contexts the clients and volunteers talked about the closeness of the relationships by likening them to family. In the informal sphere, trust allowed older people to accept help from neighbours as in the case of the HCS client who had given her neighbours keys to the house. This is important as it has been recognised that when trust is limited to the nuclear family or spouse alone, people have lower levels of social capital. Social capital increases as the radius of trust widens to encompass a larger number of people (Realo, Allik & Greenfield 2008).

3. Building Bridges

The main way the literature recognises that different networks produce different benefits is to distinguish between ‘bonding’ and ‘bridging’ social capital (Woolcock & Narayan, 2001; Putnam, 2000, Leonard & Onyx 2003). Where there is a clearly defined group or community it seems useful to ask about the social resources within the group (Bonding) and those external resources that the group can access through social connections (Bridging). So for a day care centre it makes sense to distinguish between bonding relationships among staff, volunteers and clients within the centre and the bridging connections to people or groups beyond the centre. For Home-Care clients the group is
less obvious. It could be defined as the household and the people who come there to provide care such as neighbours, family members, paid workers and volunteers. Bridging then refers to networks beyond the household.

All the CBDC coordinators made connections into their communities as part of their job. However, some centres seemed to mentor making vital links between clients, carers and other services. Mentoring connections was more than just giving information. It was about assisting them through the emotional issues and gradually introducing new experiences to the clients,

What I find with a lot of our carers, once they actually get the confidence and the client’s doing so well, we can quite often then talk them into a set respite time at one of the other places. They wouldn’t have considered it before but because the client’s done so well for the day, it’s really made a difference to their life and that happens quite a lot. We also give them a good transition into permanent care because the carer may not have even thought that they would consider the idea and so they just keep plodding along and plodding along and trying to cope (Worker, dementia specific CBDC).

Other workers also made a particular effort to build bridges between people and support groups and were appreciated by the carers and clients,

The worker came to our house that was the start of the assistance. Coming to these groups has been absolutely wonderful. We are involved now with four groups, all offshoots of Alzheimer’s Association...It’s opened up a whole new world into Alzheimer groups and things (Carer, centre-based support group).

Among the volunteers at the Chinese CBDC was the woman who had started the group ten years ago. She has also started a number of other groups and activities for elderly Chinese in her area,

I have lived in Riverwood for 20 years and have been involved with the Centre. ...Every Sunday I bring the people to shopping. I go... bible study reading the bible. We have the Chinese school. We have meetings. We have to visit them. We have many, many things. We want to know, what can we do? How can we help you?

Happy shopping
The most proactive, in terms of building bridges, among the informal carers we spoke with was David who rescued an elderly man from an abusive situation and put him in touch with his family,

   And I took him out of that house and he came to live with me. I could see there were all these bad things going on ... his carer was leaving him for two weeks at a time. He was paying the whole rent on the place so I got involved... (getting) help it’s been just wonderful to see his world open up. The biggest thing I have done is help him connect with his family (Carer/ friend for a HCS client).

Leonard and Onyx (2003) found that professionals such as doctors and ministers of religion could be particularly effective at building bridges but only when they had first earned the trust of the community. There were signs of this important role in at least one centre where a local Minister volunteers regularly. He said,

   I had only been here a couple of weeks and another helper here rang me, he trusted me, he had fallen over at the footy and wanted help... Another guy who has come here has very strained relationships with his family. He rings me once a week to say hello to me.

This category is one of the smallest, but we felt it important to include. If social networks and connections are to be encouraged then building bridges between people, services, and the local community is an important aspect of care providers’ roles. The fact that we had the least amount of data for this would appear to indicate that it is not seen as a priority.

4. Barriers to network development
Across the two samples were discussed a number of barriers to engaging, building and maintaining social connections. These can be grouped into barriers emanating from existing social norms and barriers emerging from individual circumstances.

No longer being able to drive, lack of public transport or being unable to use it, deafness, friends moving inter-state and limiting their travel, friends not understanding the drain on a carer, and the lack of respite from caring were all barriers to network maintenance and mutual support.

- Barriers arising from social norms
Social norms can be powerful forces shaping social behaviour (Ajzen 1991). While we should be cautious about judging the influence of social norms in shaping an individual’s choices, there was evidence in this study of the powerful influence of two social norms. The first social norm concerns gendered expectations in caring where women are constructed as carers. The second is an expectation about older people being as independent as possible. Both these norms have the potential to limit social networks, as discussed below.

Gendered expectations of caring:
A tacit assumption of most women carers in the study is that they will provide the care. This assumption coalesces with the broader social norm that husbands will be cared for by their wives, a norm that in our view could limit the social networks of both the wife and the husband. Members in two centre-based carers groups in particular talked about the unconditional love they have for their husbands (most of whom had dementia) and the unquestioned assumption that they would care.
But they also stressed that they need respite and acknowledged that at times they felt angry and exhausted due to the care burden,

I have been though purgatory. My husband has been on (various medications) and getting the right doses...he has been very abusive and believes he has been given the wrong doses. I go to counselling for myself once a month and I unload and I cry (Carer).

One of the female home care workers talked about the importance of compassion and that the work only becomes meaningful when you are prepared to go to extra lengths rather than just providing a prescribed service. This female worker chooses to add a voluntary dimension of care-giving to her paid work. Indeed, a number of the female workers did extra unpaid work for their clients; it seemed to be the rule rather than the exception. In the quote below one worker emphasises that she clocks off from work and that she is insured thus reinforcing the norms of the workplace. She went on to give an example of providing additional services,

Her son was her main carer, and he fell off a ladder and now he’s just a vegetable really and she wanted to get her hair done to go and see him ... so on my way home what do I do, I take her to the hairdressers and pick her up. You know little things like that that aren’t our job, but I make sure I’ve clocked off, and I’m insured. ... They don’t last in the job that long if you don’t have that compassion.

The only time a woman talked about limits was in her role as a formal care worker. She repeated “home time is home time” making it clear that this was her mantra.

Informal care networks were markedly gendered. One example is a woman and her daughter caring at home for her mother. They were very certain of the value of the caring role and were both studying aged care related courses. They were quite determined that they would not put their mother/ grandmother in a nursing home,

If you see it as a burden it’s not going to work because mentally you’ve made it harder....and I can sit back and say “Geez I am lucky to have had this experience full-time because others don’t”. It’s a golden opportunity and I think you have to approach it like that (Female carer).

In contrast the woman’s brother who lived up the road wanted to put their mum in a home and “needs to be booked a couple of weeks in advance” to assist with his mother’s care.

An elderly HCS client had her adult daughter and son living with her. Both children were in full-time work but did not pay board. However the daughter did the majority of the domestic chores. The son, who was divorced, brought his children home regularly and the elderly woman assisted him with their care,

My son’s children come here every [regularly] weekend. ... I just wish it wasn’t [so regular]. I have dropped a couple of hints but he is not listening! Isn’t that dreadful! (Home care client).

Another carer said her two daughters are helpful, but her son is in denial and will not accept his father’s diagnosis of dementia so he does not offer any assistance. A male volunteer talked about the importance of not doing too much for the clients, although he also mentioned a number of small
tasks that he helped with from time to time, such as changing a light bulb for an older client who was trying to cook in the dark.

A feminist critique of social capital (e.g., Leonard & Onyx, 2004) identifies the risk that the valuing of social capital will increase the pressure on women to take on more unpaid community maintenance work. However, the prominence of social capital also allows for greater public recognition of community maintenance or development work. This is reflected in the development in a number of countries of satellite accounts to measure unpaid work. Leonard and Onyx (2004) argue that there is still a risk that the public/private divide continues and further, that men’s community networking will be given more recognition than women’s community networking (Leonard & Horsfall 2010).

**Remaining independent:**

Independence, and particularly residential independence, is a strong norm among elderly people in Australian society (Walker & Hillier 2007; Hunter 2008). Almost all the HCS clients and carers spoke about trying to be independent and doing as much as they can for themselves,

*I’m quite independent as far as getting about and looking after myself, shopping and that kind of thing. Would your daughters help you? If need be. I try not to. They would both drop everything at the drop of a hat and I’ve told them, if we come to desperation circumstances, we will do that* (HCS client).

*We’re trying to remain as independent as we can and need help maintenance wise* (HCS client).

Formal carers and volunteers sometimes were able to advise clients about the availability of aids or services to help them retain their independence. Veterans had access to more assistance than other clients in this regard,

*There are all sorts of services they have which are designed to keep people at home, I had difficulty with my clothesline...on the place where I stood because it was all tree roots, and I was terrified I was going to fall over, and this lady [the OC] said I’ll get Home Care or Home Front or something, or some other department, and tell them what you want and they’ll make somewhere for you to stand. And they did* (HCS client).
The norm of independence had some less desirable effects whereby people did not access the services they needed in a timely manner,

I don’t think people realise there is a lot of help out there that they can get access to, but pride perhaps...They all want to feel that I can do this, I can manage....They do need a lot of extra support...(MoW volunteer).

Men were more likely than women to set limits on receiving care. In this way the gendered nature of caring and the social norm of independence fed each other, to the detriment of clients and carers. Women carers reported feeling trapped because their husbands did not want strangers in the house or to receive help from people other than their wives. The older male client who lived alone talked about the lengths he went to avoid his neighbours who seemed to want to be helpful. The desire to be independent can have the opposite effect when people do not access services that would assist them to stay well,

It is important that people start to come here when they can still communicate and be involved in activities. It is a prevention measure coming here. HACC tend to think about sending people here when they are wheelchair bound when they are already at that stage they are unable to participate. They need to come before that (CBDC worker).

A woman who talked about her difficulty in asking for help said that she would appreciate some guidance accessing services,

It is really hard to find out what services are available, how to claim eligibility in a way the government will accept, you’ve got to tick the right bloody boxes. I find it hard to ask for help but I would accept someone coordinating help on our behalf (Carer).

Asking for information from another carer

- Circumstantial Barriers
A significant barrier to older people being engaged in the community across both samples was frailty and disability. A number of participants spoke about permanent disability, increasing frailty and fears associated with increasing frailty as barriers to getting out. One female carer spoke about her husband being forcibly excluded from a society he had long been a member of because of inappropriate verbal behaviour due to his brain damage. Her husband found this rejection in the social sphere very difficult to bear. Others spoke about the death or frailty of friends as contributing to losing interest in socialising,
you see, my friends are handicapped as well, two of them, and their husbands have heart trouble. My very best friend she’s had a major heart attack. We used to meet once a month, but we can’t do that anymore. I’ve lost interest in all that now (Female carer).

One man worried that his memory loss would inhibit meaningful connection in social situations,

my memory is failing…I spend my time trying to remember things I should remember. I think well, what’s that fellow’s name I used to know. It worries me; I think I’m going bananas.

The demands of caring for someone with dementia can have a strikingly detrimental impact on maintaining social connections. One CBDC that caters for people with dementia has had to limit its outings due to clients feeling ‘lost like little children’ outside of the centre. Dementia sufferers having difficulty coping outside of routine and being very dependent on carers reduces the social life of their carers. Three female carers spoke about their desperate need to get out of the house and enjoy company other than that of their husbands, who otherwise wish them to remain at home, with one saying,

Bob is capable of going down the street by himself with a list of things to buy, he’ll continually go down and buy these things. But then there’s no reason for me to go outside the house because he’s done the shopping! So I really have to stand my ground and say I’m going to go out for a coffee – Bob has to come - because if I didn’t I wouldn’t get out of the house!

Caring for her mother with dementia was described by one woman as,

a bit like having an under 2 year old. It is incredibly restricted. I cannot plan anything and my whole life revolves around mum and her needs.

Another unhelpful dynamic thwarting social connection is when carers don’t ring other carers due to not wanting to further burden them. A carer in the second sample commented,

We carers don’t communicate much. We are isolated and become introspective or are just so busy caring. I don’t ask other carers for help as they are in the same position.

This observation can be contrasted with carers in the first sample who regularly attend centre-based groups and derive much support from the groups. They speak freely about the care burden with each other at the group and also have initiated contact with each other outside the group meeting.

Restrictions to individual mobility including distance lived away from services was another barrier to maintaining social connections. This barrier can be recognised in the absence of having suitable transport to assist people to get out and maintain social connections. For example, one older person who normally goes to the shops with a neighbour was unable to go shopping due to the neighbour hurting her back temporarily. One older man said,

I was a member of Legacy but I can’t go to any of that now. I can’t walk. I can’t walk up that hill!

Another barrier to making connections is a lack of mentoring. It would seem older people and their informal carers who are living in their own homes often do not know how to access needed services
due to no-one having modelled or taught them. This predicament can be contrasted with the experience of some carers and clients attending CBDC who are mentored in making service connections. One isolated carer who does not have access to mentoring said,

_We were not given any rehabilitation in relation to his stroke. It is really hard to find out what services are available, how to claim eligibility in a way the government will accept, you've got to tick the right bloody boxes. I find it hard to ask for help but I would accept someone coordinating help on our behalf._

In the CBDC sample, **staff turnover** seemed an impediment to sustaining connections. This is pertinent particularly when a group has not properly bonded, for example, one carers group which had not been meeting for long asked each other “_will we meet if the worker leaves?_” In contrast, a bonded semi-rural CBDC group have kept meeting over the years despite staff changes,

_We are very unhappy about (the coordinator) leaving. Every time we get used to somebody they decide to take her away. She has been here 5 years. It takes that long to remember their names! (Client)_

When it comes to accommodating people with dementia, volunteer-run social groups have their limits. A female carer’s husband used to enjoy going to a local Men’s Shed but he has deteriorated, and the volunteers at the Shed haven’t the skills to look after him,

_He hasn’t been well enough to go this year. And now that he’s having these mini-strokes I don’t think it’s fair on the other men for him to go. They’re not baby-sitters. But prior to that he just thoroughly enjoyed it and the men liked having him there because they only had 2 mechanics. They’re all volunteer’s._

Another barrier to elderly frail people having social connection is when a carer acts as gatekeeper. One client receiving in-home care had had a previous carer who prevented him from seeing family and was otherwise abusive over a number of years,

_She was smoking (marihuana). And then there was violence one night when she hit him... she wouldn’t let him see his family. It was real abuse._

Some older people choose not to engage in their community. This is perhaps less a barrier and more an individual preference. One carer said,

_We’ve never been terribly social and it’s not that the possibilities aren’t there but that we have chosen not to accept them._

While we have separated the barriers in order to bring attention to their significances, they interconnect in many ways. For example, a husbands’ need to be seen as independent means that
he will only rely on support from his wife. Her gendered socialisation as a carer means that she fulfils this role perhaps to the detriment of her own social life and mental health. Or, as people’s skills diminish they fear being seen by others as dependent so they isolate themselves further, refusing to use the help available, or to go out into the community as often. This compounds the problem as people’s skills continue to diminish as they are not being practiced. Additionally, the community’s skills in caring and accepting age-related differences becomes less as the general public is not having opportunity to accommodate the frail aged in everyday life.

5. Health & Wellbeing
While the focus of this project was investigating how social networks are formed and maintained through CBDC and in-home care respectively, much information also emerged about health and well-being outcomes of social network participation. We found that CBDC are places that create, nurture and sustain important connections that have health and wellbeing benefits particularly for older clients and volunteers. As the researchers were introducing themselves at one centre, a woman stood up and shouted my doctor told me to come here and it has saved my life! In short, it seems that meeting together regularly with other people is good for your health.

Clients spoke about specific health benefits gained from participating in CBDC,

You have to be connected with people, you have to be. You know sometimes I think it’s very therapeutic, sometimes I really don’t like seeing people, it’s like doing exercise, but once I see them I think gee I enjoyed that!

Playing euchre helps your brain stay alive. Playing cards helps you stay younger. You’ve got to think how to use those cards!

Coming here has cured my depression.

I haven’t danced in years
One client explained how her family has noticed the difference that coming regularly to her centre has made,

   My son said to me ‘Mum you have been so happy and we can tell by your voice that you are happy being with (the centre) and they’ve made such a difference with you…you’re a different person, a completely different person. You don’t go crook at us all the time.

Staff also made comments about health benefits of people meeting together at the centre. One worker purposefully took members of the research team aside to commend the preventative effect that coming regularly to CBDC has for the men,

   At home they tend to lose their communication skills because they are not practicing them. Here they can. It is very important that people start to come here when they can still communicate and be involved in activities. It is a prevention measure coming here.

   A lot of them have had depression. I often hear things like ‘I am on my own, I am lonely’. They don’t want to miss the group: The contact. The benefits are socialisation, mental stimulation getting out.

Another CBDC worker said,

   Dancing is a great exercise. All these elderly people are dancing happily and feeling young at heart.

Carers also spoke to us about how the changes they have noticed in their loved one since becoming involved in CBDC,

   Being a carer I notice things are different when she comes here, she is now doing things. Making chocolates, not that we saw any of them at home! It took us quite a while for us to convince her to come here. But once she got here she seemed very, very relaxed. Just seeing her be with other people, it is really, really good.

   Doing things

Carers and staff participating in centre-based support groups spoke about protective factors arising from centre participation that build individual and family wellbeing,

   I came here as a migrant over 60 years ago. And that means I have always made decisions and done things on my own. And to let that go… that is a hard thing. When I came here I learned that you don’t have to do everything on your own. Still I am a control freak. I have to learn to let go. Coming here, makes this easier for me” (Carer, Centre-based support group).
We feel free, we are free to speak here. That’s what we do here, we let go of our anxieties and we go home and we feel a bit better about what we do. Here, I can calm down. I have time to relax for a while (Carer, Centre-based support group).

What I find with a lot of our carers, once they actually get the confidence and the client’s doing so well, we can quite often then talk them into a set respite time at one of the other places. They wouldn’t have considered it before but because the client’s done so well for the day, it’s really made a difference to their life and that happens quite a lot. We give them a good transition into permanent care because before the carer may not have even considered the idea (Coordinator).

The finding that meeting together regularly with other people is good for your health is unsurprising as the literature demonstrates that having social connections, or strong social networks, is good for people’s health and well-being (Rowe & Kahn 1997; Zunzunegui et al. 2005). There is evidence that being part of a social network is a significant determinant of longevity for men (Zunzunegui et al. 2005). To compliment this, our research findings speak to the social and communication skills benefit of older men meeting together regularly. Indeed, time spent with friends has been found to have a positive impact on the survival of older people whether or not they actually engage in leisure activities together. Maier & Klumb (2005) found it is other people’s presence that is advantageous rather than the activities undertaken. There are of course, some people that prefer their own company (SPRC cites Mavandadi, Rook & Newsome 2007) and we did not question, or probe, when people stated this. However, we do wonder if the fear of ‘being a burden’ or being seen as incompetent or unproductive might influence this preference at times.

Methodological findings

A clear finding of this project relevant to the methodology used is the importance of establishing social connections. In order to gather meaningful information about the social networks of older people and their carers, the research team needed to work at forming new connections with CBDC programs and other care providers. These networks developed through having several meetings with centre coordinators and other formal carers. In these meetings trust developed and the researchers learned much about the philosophy and practice of elder care. The integrity of the research aims and design can be demonstrated through this; social networks had to be built by the researchers in order for us in turn to learn about social networks.

To the best of our knowledge this is the first time that Photovoice has been used in researching with older people, especially people who are frail and receive support services. We chose to use this method as we wished to hear the voices of older people and their carers as well as staff and volunteers. We also wanted to use a research method that was as inclusive as possible, enabling people to join in – and perhaps lead - the research conversations. Using visual images provided by the participants served to elicit interesting and lively conversations about the things that people, firstly, wanted to tell us about. It has also enabled us to write a report that shows what people think is important in terms of this research. This serves to make sure that older people themselves, their carers, staff and volunteers have their voices heard about this research in a more direct manner than may otherwise have been possible. One CBDC coordinator gave us this feedback about the method,
Looking ahead: Recommendations and conclusions

This research draws from social capital literature to frame an understanding of the collective benefits derived from caring for elderly people. From our in-depth discussions with 158 older people, their carers, staff and volunteers it is clear that caring for older people grows social capital, via networks and connections for the older people themselves and for the people supporting them. We found evidence that: older people both build and maintain social networks; that providing care (carers, staff and volunteers) helps build social networks and social capital and, finally, that both bridging and bonding forms of social capital (Putnam 2000) is generated by elderly people and by the people supporting them. Overall our data shows that social capital is both used as a resource and is further developed in the process of supporting people as they age. Having said this, it should also be recognised that older people’s social networks are not infinitely resourceful and this is especially the case when needs are greatest (Litwin 2007).

It is clear there is a great deal of untapped potential and a number of barriers to further developing social networks. Our recommendations focus on providing support to organisations and care providers in carrying out social networks development functions and working to overcome the barriers we discovered. We recommend the following:

1. An ongoing funding mechanism to increase the capacity of CBDC programs to continue their social networks facilitation role. CBDC programs are clearly beneficial for maintaining and growing the social networks of older people, volunteers and informal carers.

2. Funding providers and policy makers to further endorse, support and strengthen the social networks building functions of in-home care work. The maintenance and development of older people’s social networks is as necessary to their wellbeing as food, cleanliness and activities. Notions of wellbeing among older frail people and their carers based merely on functional assessment are outdated. Visioning quality of life must include notions of good social relationships, help and support; living in a home and neighbourhood that gives pleasure and which feels safe, is neighbourly, having access to local facilities and services including transport; engaging in hobbies and leisure activities as well as maintaining social activities and, retaining a role in society (Gabriel & Bowling 2004). Formal carers and volunteers providing in-home care and domestic assistance play an important role in maintaining or growing the social networks of older people.

3. There is much scope for aged care workers and volunteers to teach/ mentor older people and their carers in how to build social connections and in how to be self-advocates. Some
older people and their carers are bewildered by ‘the system’ and would benefit from HACC-funded services mentoring them in self-advocacy skills.

4. **Training and professional development opportunities where staff can learn about modelling social network formation to be increased. CBDC programs that are skilled in mentoring social connections can teach other CBDC programs in how to do this role better.** This research project revealed some best practice examples of services mentoring older people and their carers in how to establish social and care connections. One clear example of successful mentoring was demonstrated at Gilgai Day Care Centre where staff go to great lengths to establish trust, develop appropriate protocols for community engagement, and ensure the participation of the family & community, not just the client, in beyond-centre activities.

5. We found some tension between providing a service, caring and the needs of clients – the most obvious being the meals on wheels volunteer who found a client sitting in the dark because she was unable to change the light bulb. In situations like this some paid carers and volunteers are unsure about whether to help the client or how to obtain the required help. Some helped in their own time at their own risk. Some clients relied on ‘private arrangements’ to meet their needs. This at best masks unmet need and at worst could expose clients to exploitation. Although we appreciate that occupational health and safety regulations, duty of care, privacy legislation and risk management procedures have been developed to protect clients, staff and volunteers, we found that the risk is often just transferred from one to another. Care giving and social networking can sometimes be inhibited in these situations. **In order to maintain a person centred approach and to ensure that service provision enhances care giving and social networking, we suggest a continual cycle of review of systems, procedures and regulations to identify the optimal solutions.** Organisations delivering in-home care services can choose to instruct workers to limit their contact with clients and simply ‘do the job’ (deliver the meal, conduct the showering, do the cleaning) or, to encourage staff and volunteers to add the communal aspect that consciously puts the care into care-work and builds connections and networks. If they choose the former then clients are at risk of being depersonalised and further isolated. At present the workers and volunteers are left to make the difficult decision about ‘caring’ for themselves. Often they end up breaking the rules and getting personally involved. As Onyx (2009) found, some of the best examples of volunteering break the rules set by professionals. We found that in the best examples of caring work the worker and client formed a relationship where the worker now ‘cares about’ (Tronto 1993) the client as well as doing care-work. If organisations choose to acknowledge the centrality of ‘communion’ (Leonard 1997) for care-work, staff and volunteers would need to have this role acknowledged and supported. It is not acceptable to simultaneously ask workers to make sure each client is alright but also to ask them not to get involved. We suggest that service providers and funding agencies include these concerns in regular review of systems, procedures and regulations to identify the optimal solutions.

6. This research project revealed that older people’s engagement with CBDC has a preventative function in terms of helping maintain social and communication skills. Insofar as this preventative effect occurs, **older people should be encouraged to participate in CBDC programs at an earlier stage of frailty.**
7. Further research should be conducted into: the role of gender norms in elder social networking; the benefits of engaging in cultural-specific and gender-specific CBDC groups vs. mixed-cultural and mixed-gender groups to increase older people’s social networks; how the norm of ‘independence’ and ‘not being a burden’ works against growing and maintaining social networks in elder care.
References


Leonard, R & Horsfall, D. 2010 ‘Mapping the role of gender in caring networks of older people receiving services from Third Sector organisations’, ISTR 9th International Conference "Facing Crises: Challenges and Opportunities Confronting the Third Sector and Civil Society" Kadir Has University in Istanbul, Turkey, on July 7-10, 2010.


Appendices

Sample 1 Project Information Sheet

Sample 2 Project Information Sheet

Consent Form - Sample 1

Consent form – Sample 2

Question Schedule Sample 1

Question Schedule Sample 2
An invitation to join
The Care Networks Project:
How caring grows community

How do HACC funded centre-based day care services help to grow the social networks of frail older people?

Ageing, Disability and Home Care (ADHC) has funded a research project to investigate the active engagement of frail older people living in the community. The research will be conducted by an experienced team from the University of Western Sydney. The project has ethics approval from the University of Western Sydney, HREC Approval no. H7340.

The Care Networks Project: An overview

The aim of this project is to document how HACC funded services grow the social networks of elder people. To do this, we would like to engage clients, their carers and Centre staff about activities that happen in the everyday life of Centre Based Day Care. To ‘capture’ the caring and social activities that occur in Centres, the project will use a technique called Photovoice. We will provide clients, staff and unpaid carers with disposable cameras so they can photograph people, places, tasks and events they feel are significant in the life of the Centre. These photos will be used as visual discussion prompts in a group interview.

The Involvement of your Centre

From planning stage to completion of the Centre’s involvement, the project would take 8 weeks. The table below gives a snapshot of how you and your Centre will be involved over that time.

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<td>Phone contact to researchers from managers</td>
<td>Researcher visits Centre</td>
<td>Start of Photovoice project</td>
<td>Researcher collects &amp; develops photos</td>
<td>Focus group meeting facilitated by research team</td>
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<td>Set date for visit by researcher</td>
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<td>Discuss project, managers explain preferences/issues</td>
<td>Facilitated by research team &amp; photographer</td>
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<td>Plot timeline together, set date for Info Session 1</td>
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Since receiving Home Care services have you

Made new friendships?

Learned new skills?

Gone to places you may not have otherwise?

Researching the support networks of elderly people and their carers

The Department of Ageing, Disability and Home Care (ADHC) has funded a research project to investigate the active engagement of older people living in their own homes. The research is to be conducted by a team from the University of Western Sydney. The project has ethics approval from the University of Western Sydney, HREC Approval no. H7340.

The research team want to learn about the social and support networks older people and their carers make when receiving home care services. We will ask older people and their carers if receiving home care services helps them to be involved in their community. The research team will be visiting people at home to ask these questions.

In this project a technique called Photovoice is being used. If they are willing, participants will be provided with disposable cameras so they can photograph how they are supported or how they give support. ‘Support’ can mean things like: driving people places, popping in for a chat, mowing the lawn, doing the shopping, giving ‘time out’ for the carer, or ringing people to see how they are.

After the photos have been taken and developed by the research team, participants will be invited to discuss their photos.

The research findings

At the end of the project an exhibition of photographs selected by you and others participating in the project will be held. This exhibition is a way of documenting and publicly celebrating the work of caring for older people. The research team will write a report about caring and support networks that can develop through HACC funded services.

The research team will use the information collected during the project to write reports and research articles. In these publications no real names of people or organisations will be used. Photos will not be published or used unless written permission has been obtained.

If you would like to learn more about the project please speak to home care staff who visit you. Or, please contact members of the research team based at the University of Western Sydney.

Susan Evans ph. 9772 6538 email su.evans@uws.edu.au or

Lisa Armitage at l.armitage@uws.edu.au
Consent Form

Day Centre Clients, Carers, Staff & Volunteers

I, ........................................................................, consent to participate in the Care Networks research project: ‘Active engagement of older people in the community: Mapping and developing the caring networks of older people receiving ADHC services’ (longer title). HREC Ethics approval no. H7340

I have read the Information Sheet (or had it read to me) and have been given the opportunity to discuss the project with the researcher/s. Any questions I have about the project have so far been answered to my satisfaction.

I understand that the research will involve myself and others taking photos of day to day caring activities in and around the Centre over a three week period. I understand the researchers will invite participants to an information session and a group discussion meeting where photographs taken will be displayed and discussed. I understand this meeting will be audio-taped and transcribed.

I understand that my involvement is confidential and that the information gained during the study may be published but no information will be used that reveals my identity or the identity of others in the Centre.

I consent to the researchers using photographs, which may be of me, in their report to ADHC, ADHC exhibition and in research publications. I understand that my real name or the Centre name will not be used alongside photographs.

I understand that I can withdraw from the study at any time, without affecting my relationship with the researcher/s or the Centre now or in the future

Signed: ........................................................................

Participant’s Name: ........................................ Date: ..............................

If you are signing on behalf of a participant unable to sign, please complete the following:

Name: ........................................................................

Signature: ........................................................................
Consent Form for Clients, Carers, & Staff receiving or providing HACC funded Services

I, ........................................................., consent to participate in the Care Networks research project: ‘Active engagement of older people in the community: Mapping and developing the caring networks of older people receiving ADHC services’ (longer title). HREC Ethics approval no. H7340

I have read the Information Sheet (or had it read to me) and have been given the opportunity to discuss the project with the researcher/s. Questions I have about the project have so far been answered to my satisfaction.

I understand a researcher will meet with me and this meeting will be audio-taped and transcribed. I understand that my involvement is confidential and that the information gained during the study may be published but no information will be used that reveals my identity or the identity of others.

I understand that I can withdraw from the study at any time, without affecting my relationship with the researcher/s.

Signed: ............................................................... 

______________________________________________________________________________________________________________________

If you are signing on behalf of a participant unable to sign, please complete the following:

Participant’s Name: ..........................................................Date:........

Your Name: .................................................................................................

Signature: .................................................................................................
Sample 1 Question Schedule

Photo reflections

Is there a photo you would like to talk about?

If I asked you to give it a title, what would that be?

Does the photo tell you anything about the relationships people have here?

Individuals’ experience of Centre

Background Information: how did you hear about the centre? Have you lived in the area long?

What keeps you coming to the centre?

What do you enjoy doing with people here?

Have you made close friends through coming here?

What sorts of things are talked about? Done together here?
<table>
<thead>
<tr>
<th>The Centre as Network</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do you see, or have contact, with any of these people outside of the centre?</td>
</tr>
<tr>
<td>Are you involved with other groups or activities in the community?</td>
</tr>
<tr>
<td>Has coming to the Day centre helped you to be involved with those activities?</td>
</tr>
<tr>
<td>Helped you to keep being involved with those things?</td>
</tr>
<tr>
<td>Is there anyone you have met through coming to the centre that you might see now and again (eg. Cleaner, baker)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Evaluations of the Network</th>
</tr>
</thead>
<tbody>
<tr>
<td>What are the positive consequences of people coming together? Any benefits beyond these things for the group?</td>
</tr>
<tr>
<td>Do clients and staff/ volunteers build connections with the broader community through coming to the Centre? Have you personally formed such connections? (if so) can you tell me about them.</td>
</tr>
</tbody>
</table>
Sample 2 Question schedule

1. How long have you (or the person you care for) been receiving in-home care services? Can you tell me about this care/support?

2. For client: Who else supports you? What support do they give you?

3. For client: Are you involved in other activities during the week? See other people? (Either at home or outside the home)

4. For client: Does the care you receive help you to be involved with these activities/people? How does it do this?

5. For carer/volunteer: Does the care you provide help you to be involved with community groups/activities outside the home? How?

6. For carer/volunteer: has doing caring work enabled you to form new friendships or new support networks?

Complete consent form.