

Who Will Look After Her When I Die?

**Report on the Ageing Carers
of People with a Disability Project**

**Project Report by
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for Commonwealth Carer Respite
Centre/Carer Links West**

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Executive Summary

The Commonwealth Carer Respite Centre / Carer Links West (CCRC/CLW) works with unpaid family carers living in the Western Metropolitan Region of Melbourne. The service operates with three specialist teams (Aged, Disability and Mental Health) who work directly with carers and with other service providers.

The CCRC/CLW Disability Team had been working with ageing carers for a number of years as an integral component of its core work. There had been growing awareness in the program and in the field in general of the particular needs of ageing carers. The Ageing Carers Project provided an opportunity to extend this core work with carers through a community development approach.

The twelve month Ageing Carers Project began in November 2003 with two aims: first to assist ageing carers of people with disability in their caring role and second to plan for continuity of care for the person with a disability in order to ease concerns that ageing carers may have about the future.

The project focused specifically on the needs of carers and parents who are 65 years and over and who care for someone with a disability. The person they care for was generally their adult child but in some cases was a grandchild.

Many of these carers made a conscious decision long ago to care for their child with a disability at home. This decision was often made at a time when the only option was institutional care. Often these carers have not kept up with the many changes in the service system, and as they now approach the system and request permanent placement they discover that it is limited principally to crises.

Research and Literature Review

The first stages of the project included a literature review and consultations with service providers. It became clear that the themes emerging from the review of the literature are very much in line with the feedback from service providers who come in contact with ageing carers as well as with those identified by CCRC/CLW. They can be seen to particularly converge around the need for a respectful and flexible approach by services towards this group of carers.

The themes emerging both from the literature review and the feedback from service providers informed the strategies that were developed for the Ageing Carers Project, which focussed on information, emotional support and planning for the future.

Project strategies

- ◆ Information Sessions. To address the identified need for access to information, a series of five information sessions was organised.
- ◆ Ageing Carer Support Group. The intention of forming an Ageing Carer Support Group was to provide an opportunity for ageing carers to come together to share their stories and gain support from each other. (The group continues to meet monthly.)
- ◆ Carers Morning Tea.
- ◆ Carers Retreat. A carers' retreat was organised for a group of older carers. The aim of the retreat was to give carers an opportunity to experience time away from their caring role, to meet with other carers and to participate in workshops and activities.





The strategies aimed to specifically meet the principle needs that emerged in the review of the literature and in the exploration of issues for service providers.

In the light of carer responses there was strong evidence that each of the strategies succeeded in supporting and informing carers.

Recommendations

The recommendations of this project are intended to be practical: they aim to directly influence the day to day practice of CCRC/CLW.

1. That CCRC/CLW continue to develop initiatives that support ageing carers accessing respite for the first time.
2. That CCRC/CLW gives consideration to the needs of carers from 55 years of age.
3. That the CCRC/CLW continues to support initiatives that bring together ageing carers.
4. That the CCRC/CLW recognises and respects the wishes of ageing carers.
5. That the CCRC/CLW endeavour to influence the service system to improve the quality of care provided by direct care workers.
6. That the CCRC/CLW remain alert to opportunities that might improve transport options for ageing carers.

In addition the following two recommendations, which fall largely outside the sphere of influence of the CCRC/CLW are crucial to any consideration of ageing carers.

7. Service models need to be better resourced and flexible to meet the varying needs of ageing carers.
8. The service system needs to have a dual focus on both the carer and the person being cared for.

Introduction

This report documents an action research project that set out to look at the needs of ageing carers of people with a disability living in the Western Metropolitan Region of Melbourne. The project also piloted some strategies to meet these needs.

The 12 month project formed part of the work of the Commonwealth Carer Respite Centre / Carer Links West in the Western Metropolitan Region.

About the Commonwealth Carer Respite Centre / Carer Links West (CCRC/CLW)

The CCRC/CLW works with unpaid family carers living in the Western Metropolitan Region of Melbourne. It offers assistance and information for families and people who care for a family member or friend who may be:

- ◆ an elderly or frail aged person
- ◆ a person with dementia, or dementia and challenging behaviours
- ◆ a person with mental illness
- ◆ a person with a disability (0-65 years of age) A disability can mean an intellectual or physical impairment, or a chronic illness

The service operates with three specialist teams (Aged, Disability and Mental Health) who work directly with carers and with other service providers. The teams provide support, referral and information about the service system, and work within the system to develop new services and opportunities. Much of the work of the service involves using brokerage funding to support carers in their caring role, and predominantly around respite.

Background

The CCRC/CLW Disability Team had been working with ageing carers for a number of years as an integral component of its core work. One hundred ageing carers were registered clients of the Disability Program at the beginning of the project in November 2003, but in the mix of the work carried out with carers of people with disabilities there had never been the opportunity to focus specifically on the needs of this group. The team had been providing one-to-one support and information to ageing carers and limited brokerage to assist with short-term respite options.

There had been growing awareness in the program and in the field in general of the particular needs of ageing carers. This increased understanding resulted in part from a growing body of work highlighting the difficulties faced by ageing carers. In particular the work of both Chris Bigby (Senior Lecturer, La Trobe University) and Shirley Carlos (Disability Policy Worker, Carers Victoria) informed the early stages of the project proposal. Also of significance was some work undertaken in the region by the Senior Clinician at the South West Area Mental Health Service, Deb Carrin, who had conducted research into ageing carers and depression using focus groups of ageing carers.

The Ageing Carers Project provided an opportunity to extend this core work with carers through a community development approach.

A project brief was developed (Appendix 1) which puts forward a rationale based on this practice knowledge and policy work. This rationale in part identifies current service system gaps in the light of the growing understanding of the range of particular needs experienced





by this target group and the uncoordinated efforts from within the system to begin to meet those needs. It also makes note of the vulnerability of ageing carers: even where they are linked in to one service, they typically are not aware of the broader system and their entitlements. This leaves them at risk in times of crisis, particularly as many carers made a conscious decision long ago to care for their child with a disability at home, and since then the option of a permanent placement has shrunk to vanishing point without their knowledge.

Project Aims

The twelve month Ageing Carers Project began in November 2003 with two aims: first to assist ageing carers of people with disability in their caring role and second to plan for continuity of care for the person with a disability in order to ease concerns that ageing carers may have about the future.

Project Objectives

The project focused specifically on the needs of carers and parents who are 65 years and over and who care for someone with a disability. The person they care for was generally their adult child but in some cases was a grandchild.

The objectives of the project were to:

- ◆ seek hidden ageing carers through strong links with service providers and the sector as a whole, especially those partners nominated in the project brief (see Appendix 1)
- ◆ facilitate the planning for continuity of care by:
 - ◆ co-coordinating the delivery of “futures planning” workshops for ageing carers across the Western Metropolitan Region
 - ◆ assisting ageing carers in their role by linking them to existing support systems including respite services, peer support and financial assistance
- ◆ provide intensive support to first time respite users
- ◆ link with the aged care system where appropriate for carers’ own aged care needs
- ◆ collaborate with the disability service system, ethno-specific and Aboriginal and Torres Strait Islander agencies, the aged care system and Divisions of GP
- ◆ develop appropriate resources, such as a GP checklist
- ◆ organise and co-ordinate a specific event or series of events (such as a carer retreat) from which friendships may evolve, and facilitate and support ongoing peer contact such as a carer support group

Forming a Reference Group

At the beginning of the Project, key service providers were brought together to form a reference group (Appendix 3) that would provide input, partnerships, links and content for the project. The Reference Group included representatives from the Victorian Department of Human Services, a regional case management agency, an adult disability day activity service, an area mental health services, the Aged Care Team of CCRC/CLW, the Disability Policy Worker from Carers Victoria and the manager from CCRC/CLW. The Reference Group met four times during the Project and provided a regional overview of ageing carers issues as they related to the progress of the project.

Methodology

Literature Review

An initial literature review was undertaken to draw out key themes pertinent to the Ageing Carers project.

This review included two research reports that were already influential in practice of the CCRC/CLW Disability Team. The first of these was a brief unpublished paper presented at a forum in July 2003 by the Disability Policy Worker from Carers Victoria titled '*Responding to older carers - what carers need*'.

The paper described work that had found that ageing carers need:

- ◆ More services: The community care system is significantly under-resourced and carers are bolstering the service system at great personal cost
- ◆ Better quality and more responsive services: Closer co-ordination is needed across the service system to create flexibility and pro activity, better training for staff and the recognition of the carer as a partner in the planning process
- ◆ Information: This needs to be in an accessible language and format, and conveyed through a relationship with trusted workers
- ◆ Education and support: This includes the need for carers to plan for the future, information about available services, entitlements and condition specific information
- ◆ Peer support through carer support groups: In a carers support group, carers can share, be heard and have their experiences validated.
- ◆ Outreach: Strategies need to be put in place to reach hidden carers. These can include co-ordination within the system as well as promotion within the community.

The second influential paper was an unpublished report produced by the Area Mental Health Team looking at the needs of ageing carers in South West area of Melbourne. The findings were drawn from a focus groups of ageing carers of adult children with disabilities.

The results of this work supported the Carers Victoria paper, and added that common issues for ageing carers are:

- ◆ feelings of isolation
- ◆ loss and grief
- ◆ stress and depression
- ◆ the dependency of the adult child with a disability on the parent.

In terms of the service system it was found that:

- ◆ the role of the carer is not given due acknowledgement and respect
- ◆ services such as respite are targeted to the needs of the care recipient and do not consider the needs of the carer
- ◆ transport is difficult to access.

Other literature included in the review focused on research examining the circumstances of carers aged over 55 who care for a son or daughter, primarily with an intellectual disability.





Australian and overseas research published in the last seven years was included.

Two areas of study emerge from this wider review. The first focused on the emotional condition of ageing carers, including carer satisfaction levels, stress, emotional issues, adjustment, loss and grief. These studies included Rimmerman and Mauraver (2001), Cummins (2001), Nankervis et al (1997), Llewellyn et al (2003). The second area of study focused on the service system and teased out debates around service planning and policy. Included in this group were Bigby et al (1999), Bigby (2000), Janicki et al (1988) and Chan et al (2001), Cummins (2001)



Consultations with the local service system

For the project to develop an overview of the work already underway in the region, and to identify gaps and unmet needs for this target group, seven local agencies that have contact with carers and parents were approached (Appendix 3). Work with ageing carers was not these agencies' core work: they primarily work with people with disabilities and as part of that come in contact with ageing carers.



The most pressing issues raised by these service providers were strongly consistent with the experience of the Disability Program of CCRC/CLW.

Findings

Findings from the literature

Ageing Carers' Health and Well Being

In terms of general health, mental health and the issues carers faced, Llewellyn et al (2003) found that the overall health status of ageing carers was poorer than that of the Australian population at large, and that there were also significant differences for 55-64 year olds in terms of poorer mental health. Bigby and Ozanne (2004) suggests that "*later life caring involves stresses associated with unending dependency, chronic sorrow, declining physical capacity, lack of formal services, social isolation, financial pressures and anxiety about the future care of off-spring.*"

Studies focusing on variables of age, well-being, in or out of home caring of off-spring, and family type, produced conflicting results. Rimmerman and Muraver (2001) compared ageing mothers of adult children living in home or out of home, regarding the factors of undesired life events, life satisfaction and well-being. The research found that mothers who were 68 years or older and who lived with a child with a disability at home had greater overall satisfaction than mothers of children with disabilities living out of home. Moreover, mothers over 68 years of age in one-parent families with children living at home had greater levels of satisfaction than two parent families with a child at home. Llewellyn et al (2003), in a study of older parents of adult children with intellectual disabilities found that ageing carers' health status varied on two dimensions. Married or defacto parent carers reported better physical health and older parent carers (69+) reported better mental health.

Whereas McDermott et al (1996) found no significant difference in carer satisfaction based on age, Llewellyn et al (2003) found that as age increases (65+) study participants were more likely to report better mental health as well as lower stress related to emotional reactions to care giving and restrictions imposed by care giving on social life. However the more time the adult child with a disability spent at home and the higher their care needs, the more carers experienced this as stressful. The research does seem to show, however, that reliance on age alone as the indicator of carer stress and burden may be misleading. Other factors such as family history, significant relationships, context and the degree of reciprocity in the care giving relationship and whether care is provided in or out of home care need to be given careful consideration. In general, and as highlighted by Bigby and Ozanne (2004) the message is consistent that in later life parents face the emotionally difficult task of beginning to let go and planning for the future care of their adult child and as parents age their internal and external care giving resources are reduced.

Issues for Ageing Carers identified in the literature:

Cummins (2001) and Nankervis et al (1997) identified issues faced by carers which fall into five main areas:

- 1. Practical needs: information and assistance with services.** Uncertainty or confusion about the cared-for-person's condition created a need for clear information about the condition, its prognosis and treatment. These problems were compounded by poor communication with health professionals. Carers also experienced the need for assistance with services including respite, home care and residential placement as well as financial and legal support. More complex service issues related to unsuitability or lack of services in a particular locality, accessing multiple services when a dual disability was involved or changes in service provision or philosophy.





2. The caring role: choices. Carers struggled with issues such as taking responsibility for caring and caring tasks. They also have concerns about separation and relinquishing the caring role as well as dealing with the expectations of other key people such as relatives and service providers.

3. The caring role: changes. Carers experienced difficulties in coping with changes in the cared-for person's behaviour, personality and needs. Carers also had to cope with impairments in their own health and well being reflected in exhaustion, ill health and stress from undertaking the carer role for many years.

4. Emotional issues. Carers experienced a range of difficult emotions including: grief caused by the cared-for person's condition or loss of former life-style; anger towards family and friends for the lack of support and to professionals and service providers for not responding adequately to the carers' needs; and guilt, anxiety and helplessness.

5. Family difficulties.

The caring role exacerbated problems with relationships, a revival or increase in past family conflict, criticisms of the carer, disagreements about future provisions of care, communication difficulties and tensions in balancing competing family needs.

Service System issues identified in the literature

From a service system perspective the following issues were raised:

- ◆ A large and increasing number of people with disabilities live with their parents well into adulthood. Due to the increased life expectancy of people with disabilities they are more likely to outlive their parents than in previous generations (Bigby and Ozanne 2004)
- ◆ The estimates of ageing parents 65 and over caring for an adult child living at home have increased from 7,700 in 1993 to 9,700 in 1998 (AIHW in Bigby and Ozanne 2004)
- ◆ Unlike other caring situations, for older parents it is the death or incapacity of carers that marks the cessation of the caring. It is the interdependence or mutual caring between carer and care recipient as parents age that poses a challenge to the traditional case management model of supporting continued caring. (Bigby and Ozanne 2004)
- ◆ There needs to be recognition of the tensions between a rights framework that is embedded in the Victorian State Disability Plan 2002-2012 and which supports choice and self-determination for people with disabilities and a family focused approach that acknowledges the role of parents in lives of adult offspring. (Bigby and Ozanne 2004)
- ◆ There is a need for services to adopt a proactive preventative approach around older carers issues, rather than being crisis driven. Studies have found that older carers initiate contact with services at a crisis point such as illness, death or noticeable physical or mental decline. Furthermore it has been shown (Llewellyn et al 2003) that ageing carers do not use family support services. Their study found that ageing mothers did not perceive the need for many services on offer. There appeared to be three reasons for this: they were from a generation without access to services and had developed coping strategies that negated the need to seek outside support; they had a strong commitment to personal responsibility, and they felt a sense of embarrassment and desire to *"keep one's troubles to oneself."*
- ◆ There needs to be recognition and resolution of value conflicts between older carers and professional workers within the service system. In addition to the reasons above,

older carers are reluctant to interact directly with disability agencies because of poor past experience, expressed fear of institutionalisation or re-institutionalisation of the family member and a perception that the system is too complex and fragmented. Ageing carers have lived through significant and fundamental changes in the system. At a time when institutionalisation of people with disabilities was the norm, they, as a parent, swam against the tide of public opinion to keep their child(ren) at home. In doing so, they acted against attitudes of rejection, segregation and institutionalisation and in many cases developed strong protective parental responses. It is not surprising then that after a lifetime of caring there can be a reluctance to give up that role, and a belief that services will not provide the quality of care that they have provided for many years. (Llewellyn et al 2003)

- ◆ The service system is oriented toward quick tangible outcomes, while ageing carers situations are typically not able to be resolved in this way. Ageing carers situations are more likely to be complex, interdependent and entrenched, with established attitudinal positions so will not unfold or transform into a situation with an identifiable “outcome” in the short time lines generally required by agencies. (Janicki et al 1998)
- ◆ Much of the literature tends to the view that there are likely to be more hidden older carers than previously understood. This means that processes need to be established that will assess the disability of the person being cared for when they may have had no contact with the service system and therefore not developed legitimating documentation. (Janicki et al 1998)
- ◆ There needs to be closer collaboration between the aged and disability service systems because in many cases they are both involved in supporting the same caring relationship. (Janicki et al 1998)
- ◆ The need to support ageing carers to plan for the future. This support in part must acknowledge carers’ reluctance to face the “*what happens when I die*” since frequently it is unclear to them who could take on the caring role. Llewellyn et al (2003) found that a significant proportion of older parents do not make plans regarding the future financial, residential or guardianship arrangements for their adult child with a disability.
- ◆ The service system needs to recognise all the household members, including potentially diverse and complex dynamics involving multigenerational and cultural issues. (Janicki et al 1988, Bigby et al 1999, McDermott et al 1996)
- ◆ Bigby et al (1999) identifies core elements of appropriate service models to meet the needs of ageing carers. They are:
 - ◆ a dual focus on the carer and the adult with disability
 - ◆ maintaining the current living situation, whilst preparing for the future
 - ◆ multiple modes of intervention including: direct work with individuals; group work; community education; systemic advocacy and resource development
 - ◆ the use of relationships to affect change (ie taking time to develop trust)
 - ◆ sustained and long-term interventions with varying degrees of intensity and degrees of assertiveness
 - ◆ working through existing support networks.

Findings from the consultations with service providers

Age appropriate social activity for the adult with the disability. Ageing carers frequently do not have time and energy to pursue this;





Long-term accommodation. There is uncertainty in the minds of ageing carers because they have no access to community residential units or similar accommodation and currently there is no growth in permanent accommodation;

Peace of mind for ageing carers that their child will be cared for when they die.

Ageing carers ask "who is going to look after my son or daughter when I die?";

Services for adult children who have reached retirement age e.g SCOPE have established a third age group for older clients of retirement age as there is insufficient capacity to allow them to individually stay in a CRU. With additional resources they can go to a Senior Citizens and participate in activities;

Programs to develop independent living skills in the adult children;

Respite when parents are ill or in a crisis many parents contact services when they are seriously ill or unable to care. For example due to hospitalisation, the level and the urgency of respite required at this time stretches the resources of services;

Support with, and counselling for emotional issues such as grief, loss, adjustment and letting go for parents who have been caring for a long time or when the adult child has acquired a disability in later life:

Awareness and sensitivity to the differing needs of ageing parents from CALD backgrounds;

Financial security is a significant factor in the lives of carers who have not had the ability to accumulate funds for retirement or their adult child's future;

Education about a changed system ageing parents view the service system as it was many years ago, and find it difficult to understand the service system as it is now;

Support with planning for the future regarding financial, residential or guardianship arrangements;

Support with administration and finances;

Better resourcing in the service system for example the amount of service is inadequate; and

Developing trust in ageing carers Ageing carers can be fearful of 'letting go' and handing the care of their child over to services they may not fully trust. Additional support is needed accessing respite and leaving their adult child for the first time. There is a need to look at ways of introducing respite for first time users, and to make transitional arrangements e.g short visits to a respite house and gradually increasing time and leading to parents leaving for longer periods.

Emerging Themes

It is clear that the themes emerging from the review of the literature are very much in line with the feedback from service providers who come in contact with ageing carers as well as with those identified by CCRC/CLW. They can be seen to particularly converge around the need for a respectful and flexible approach by services towards this group of carers. What is lacking is a strong relationship between ageing carers and service providers. The themes emerging both from the literature review and the feedback from service providers informed the strategies that were developed for the Ageing Carers Project, which focussed on information, emotional support and planning for the future.

Case study 1 — Val

Val is 84 years old she lives with her daughter Betty who is 47 years old and has an intellectual disability. Val has been caring her daughter for all of these 47 years, and since her husband passed away 20 years ago she has provided the care alone. Val had an active working life serving in the RAAF, where she met her husband.

Betty attends a day program during the days and Val is involved with the Legacy Club.

But Val frets about what the future holds.

She says "I worry about what will happen to Betty when I have gone. I'm always thinking of her welfare, but there is nothing really satisfactory. She can manage the personal side, but cannot manage the medical side. This is a great worry. I do everything, more or less, the cleaning, shopping and cooking... I'm very slow. I think if you keep moving you keep on moving...if you stop you stop. I like doing what I do, and I do what I can. Betty was very sick when she was young and, I have to, I think I spoilt her a bit...I do all the shopping ... I walk about half an hour to an hour to get to the shops. The cleaning and tidying takes longer than it used to, but it eventually gets done".

Recently Val's telephone was out of order. That meant she couldn't call a taxi to leave the house. It was 9.30 in the morning and her neighbours were at work so she wasn't able to ask to use their telephone. Val walked half an hour to the nearest phone box to report the fault with her telephone. Val missed out on the projects Information Session that day.





Case study 2 — June

June is also 84. She is the full time carer of her son Gary who is 45. Gary was diagnosed with Motor Neurone Disease 15 years ago. Prior to his diagnosis he was an active adult working in the army with a girlfriend. After progressively becoming more unwell he moved back into June's home.

He is now highly dependent on the care of others for all his activities of daily living, eating, bathing and toileting. While June now walks with a frame herself, Gary's mobility is becoming more and more limited.

A large number of services are involved -6 at last count. This includes a case manager, workers who help with his personal care needs three times a day, a masseuse who visits once a week and a worker who takes Gary out on Saturday afternoons to watch his beloved football team. June enjoys these outings as well. June loves to laugh and talk with others and has enjoyed the company and support she finds at the ageing carers Carer Support Group which we have established as part of the project.

She enjoys what she does for Gary and feels he is better off at home than in permanent care. In the past June has holidayed in Queensland for a month during the cold winter in Melbourne with her friend. While she enjoyed this annual respite Gary stayed in an Aged Care Facility. This year June's friend isn't well enough to make the trip so she'll miss out this time.

June has made a promise to Gary that he can stay at home for as long as she can keep on caring for him. So it is no wonder that June becomes teary when she talks about a recent visit to the Doctor. It emerges that the doctor has said maybe it's about time she thought of putting Gary in a nursing home.

Project Strategies

Information Sessions

"gave me a new perspective"

To address the identified need for access to information, a series of Information Sessions was organised. The sessions were held over 5 weeks. Each week looked at a specific topic with an 'expert' speaker.

The first two sessions focussed on the participant's role as a carer. An exploration of the loss and grief that can be experienced within that role was delivered by Carers Victoria. The other three sessions provided a range of information and an introduction to some relevant services. The sessions were held from 10 am till 12.30 pm, in a comfortable meeting room with lunch provided at the end of the session.

Topic	Speaker
The caring role, choices and challenges.	Education and Training Team, Carers Victoria
Loss and grief	Education and Training Team, Carers Victoria
Services and planning for the future	Department of Human Services and Care Connect-providers of services to ageing carers
Guardianship and the role of the Office of the Public Advocate	Speaker from Office of the Public Advocate
Respite services	Speaker from Commonwealth Carer Respite Centre / Carer Links West

One hundred invitations were mailed out to CCRC/CLW registered carers and ten ageing carers, including two married couples, attended the sessions.

The feedback from the Information Sessions was overwhelmingly positive:

"At first I decided not to go to the week on 'Loss and Grief', I'm glad I did, it was very good and gave me a new perspective. I have had my son for 53 years in September, I thought It only was just my family responsibility, I can see that other people have problems and I can put it in a broader sphere and see it as a community problem."

"I have enjoyed talking and listening to other people, finding out how they have to cope."

"It's great to know there are organisations working to help carers on a broad level."

The ageing carers all found the sessions interesting, informative and useful. They found it was helpful to find out more about the services available, although they expressed disappointment about the lack of commitment by the government to build supported





accommodation for their adult children in the future.

Another clear message coming from the evaluation of the session was a plea for better quality attendant care services. Carers identified a need for better trained staff with the capacity to provide the level of care required. Carers expressed a wish to be partners in providing care and to be central to the planning process.

Ageing Carer Support Group

"Other carers understand."

The intention of forming an Ageing Carer Support Group was to provide an opportunity for ageing carers to come together to share their stories and gain support from each other.

Anecdotal material from service providers had indicated that ageing carers are difficult to involve and unlikely to participate, so this part of the project was approached with very modest expectations. As it happened, it was heartening to see ageing carers' willingness to participate. They found the group a valuable space, where they could get together and talk about their caring situations in an informal atmosphere. For ageing carers who had had little involvement with services this was an important first contact, a way to meet others in a similar situation and a way to find out more information and to perhaps gain confidence to have more involvement from services in the future.

The Group continues to meet monthly for informal discussions and to share ideas and information. Some of the topics the group has looked at are the Companion Card, emergency after hours services, and new services in the region.

Feed-back from the members of the support group:

"Other carers understand what you are going through."

"If I talk to my brothers and sisters they don't understand, they say put them in a home...they don't offer any help."

They saw the support group as a place to: *"find information about where to get help", "find accommodation options", "make plans for when I die", "hear stories", "listen and talk" an "lobby to make changes".*

Carers Morning tea

"I feel pampered and special."

Ageing carers were invited to participate in a morning tea at the Windsor Hotel Ballroom in Melbourne organised by CCRC/CLW. The event brought together over 100 carers of the aged, carers of people with disabilities and carers of people with mental illness. The morning included a formal morning tea, roving music competitions and good opportunities to socialise.

Carers had the opportunity to meet other carers and enjoy some time out from their caring role. Transport in the form of taxi vouchers and respite in the form of in-home care were provided to allow carers to enjoy some time out.

The ageing carers who attended felt that it was great to meet with people in a similar situation and to break down the feelings of isolation that can be apart of being a carer.

Carers Retreat

"I feel alive again."

A carers retreat was organised for a group of older carers. The aim of the retreat was to give carers an opportunity to experience time away from their caring role, to meet with other carers and to participate in workshops and activities. The destination was Hepburn Springs, a small rural town in the heart of Victoria's Spa region.

A group of 21 carers over 60 years of age enjoyed the time out to relax and get to know each other and share their stories with one another.

The itinerary included:

- ◆ massages
- ◆ trips to mineral baths and the spa resort
- ◆ participating in a workshop on the topic of 'Looking after yourself as a carer' which was delivered by Carers Victoria
- ◆ learning about aromatherapy in a Workshop that was delivered by a local Naturopath who worked locally
- ◆ visits to shops, historic sites and a train ride to see the mountain scenery.

The carers were transported in a mini bus

Some of the more memorable moments occurred in the evenings, with sing-a-longs, dancing and a talent quest. The workers who attended were amazed by the hidden talents in the carer group: poetry reading, joke telling, moving performances of song.

Some feedback from the retreat was:

"Before the retreat I felt guilty, totally burnt out and stressed afterwards I felt relaxed, happy and ready to tackle all before me."

"I felt a bit sceptical at first but this soon changed after the first day, it was terrific to bond together and share meals together."

"I met and made new friends...I feel alive again."

"We thought that we were able to cope OK but the retreat provided us with some more knowledge about how to cope and look after ourselves."

"Interacting with other carers has been a wonderful learning experience and to chat with people living with some of the situation that you live with was a wonderful experience."





Snap shot of the people involved in the Ageing Carers Project

100 ageing carers on the books at the beginning of the project, 130 at the completion.

25 of those carers became involved in the project. Of those 25, 22 were women and 3 were men (including 2 couples).

10 of the women are now sole carers.

The carers' ages range from 55-84.

One of the carers is caring for a grandchild with a disability and the remaining carers are caring for an adult son or daughter with a disability. A number are caring for 2 people (for example two adult children with a disability or an adult child with a disability and a spouse needing care).

A number of ageing carers also care for grandchildren who don't have disabilities.

Involvement in services varied amongst the carers. Some had absolutely no services involved while some experienced a high level of in home support where the person being cared for had high support needs. The majority of care recipients were involved with a day program but a significant minority of adult children were not involved with any day program and had completely 'dropped through the cracks' of the service system, causing a high degree of stress for the ageing parent.

Of the people being cared for, the predominant disability is Intellectual Disability (ID) followed by a physical disability, Multiple Sclerosis, Cerebral Palsy or multiple chronic illnesses.

Discussion

The strategies aimed to specifically meet the principle needs that emerged in the review of the literature and in the exploration of issues for service providers.

The Information Sessions provided ageing carers with a non-threatening opportunity to consider services, perhaps for the first time, and to begin thinking about planning for the future. For reluctant users, the information sessions allowed carers to safely explore the idea of increasing involvement with services.

Carers inevitably place a higher value on the credibility of information or examples about particular services when they receive them from other carers, and the information provided that opportunity.

The support group, the morning tea and the retreat created different settings for ageing carers to experience, or at least consider, some aspects of emotional support. These group activities are also cost effective when compared with individual work such as that embodied in the case management model. An added advantage is that carers learn from several other carers rather than from a single worker they may regard with some scepticism, or even suspicion. Of course the particular value of peer support is also exercised with these activities: carer consistently state that it is other carers who most understand their situation, role and difficulties. One male carer stated that the support group was the only place he talked about his concerns and feelings about his adult child with a disability, and the difficulties he and his wife experienced.

In the light of carer responses there was strong evidence that each of the strategies succeeded in supporting and informing carers.

Recommendations

The recommendations of this project are intended to be practical: they aim to directly influence the day to day practice of CCRC/CLW.

1. That CCRC/CLW continue to develop initiatives that support ageing carers accessing respite for the first time.

These should include information sessions and forums providing support and information to first time users of respite.

For ageing carers who are reluctant to access respite, the CCRC/CLW should encourage transitional arrangements in respite houses. These could include short visits gradually increasing in duration.

2. That CCRC/CLW gives consideration to the needs of carers from 55 years of age.

Though 'aged' is generally defined as 65 years and over by government and funding bodies, practical experience shows that when a parent has been taking on caring responsibilities for an adult child, often in later years as a sole parent, they experience many of the symptoms and difficulties of age significantly earlier.

This allows for more proactive work: forward planning and where possible moves away from a crisis driven approach. As an example of this crisis driven approach is apparent in the Department of Human Services' Special Needs Register. The CCRC/CLW will build into its service the plan to contact people at a certain age with the view of working with the ageing carers to begin to put appropriate supports in place.

3. That the CCRC/CLW continues to support initiatives that bring together ageing carers.

Examples are carer support groups, social occasions and futures planning or information sessions. Opportunities for new groups to develop should be fostered.

4. That the CCRC/CLW recognises and respects the wishes of ageing carers. The CCRC/CLW will continue to work with providers to promote a cultural attitude shift that recognises ageing carers as partners in providing care, and central to the planning process

5. That the CCRC/CLW endeavour to influence the service system to improve the quality of care provided by direct care workers. This involves a collaboration with agencies who are committed to quality care.

6. That the CCRC/CLW remain alert to opportunities that might improve transport options for ageing carers.

Transport remains a crucially important issue for ageing carers and the person they care for. Carers identify that they regularly experience problems with the punctuality and reliability of the taxi service and for most ageing carers there are simply no other viable transport options.

In addition the following two recommendations, which fall largely outside the sphere of influence of the CCRC/CLW are crucial to any consideration of ageing carers.

7. Service models need to be better resourced and flexible to meet the varying needs of ageing carers. For example the Special Needs Register is crisis driven and needs to be better resourced to take on a more pro-active role.
8. The service system needs to have a dual focus on both the carer and the person being cared for.





Appendix 1

Ageing Carers of People with a Disability - Project Brief:

- Project duration:** 12 months
- Project staff:** 0.8 EFT project worker
- Target group:** Ageing carers living in the Western Metropolitan Region of Melbourne who care for a person with a disability
- Project aim:** To assist ageing carers in their caring role, and plan for continuity of care for the care recipient, in order to ease concerns that ageing carers may have about the future

Project overview

The project will include two areas of focus for ageing carers of people with a disability: work with individual carers; and work within the system.

Ageing carers will be identified and supported by the project which will:

- ◆ ensure they are linked to the support (ongoing if possible) of peers;
- ◆ ensure they are well informed about the service system and their rights and entitlements to supports;
- ◆ equip them to deal with and prepare for the inevitable changes in their lifestyle; and
- ◆ assist them to begin planning for the future of the person for whom they care.

Project Rationale

Existing networks go some way towards supporting carers of young and school aged children.

Two identifiable gaps in the current system are:

- ◆ supports tailored to ageing parents of adult children with disabilities; and
- ◆ supports tailored to ageing carers — typically, grandparents — of younger children with a disability.

The project will cater for both these subgroups and their needs.

While individual disability services such as adult training and support services are beginning to see the need to provide some information and education for older families, this is not co-ordinated across the region. Families not linked in to these services are missing out. Furthermore, many families who are linked, utilise disability services in isolation and are not aware of the broader service system and of their entitlement to access services such as respite.

Many carers made a conscious decision long ago to care for their child with a disability at home. This decision was often made at a time when the only option was institutional care. Often these carers have not kept up with the many changes in the service system, and as they now approach the system and request permanent placement they discover that it is limited principally to crises.





These families have also often relied on their own resources but as the carer ages, these resources shrink: other family members also age; people move on and move away. This pattern increasingly isolates the ageing carer.

Some families not connected with the service system have tried accessing respite in the past but an unsuccessful experience, which may have been alleviated by some intensive support prior and during, has kept them away ever since.

When families enter the disability services system at a later stage this is often at the point of crisis, when the living situation is breaking down and there is no alternative plan in place. This combination of circumstances is extremely stressful for carers and can in part be alleviated by some proactive planning.

It is often not until the point of crisis – usually associated with deterioration in carer health – that an ageing carers' role in supporting their child with a disability becomes known outside the family. There is still a pressing need for a better informed service system (including GPs and specialists as well as community care providers) that is aware of the supports available to carers such as respite, peer support, education and information.

Carers from CALD and ATSI backgrounds are particularly vulnerable as they age because they are less likely to have accessed support prior to the point of crisis.

A significant gap exists throughout the region in the provision of facility-based respite, outside aged care homes. In the existing respite houses, emergency beds and some respite beds are constantly filled by people with disabilities who need permanent placement.

Project objectives

- ◆ seek hidden ageing carers through strong links with service providers and the sector as a whole
- ◆ facilitate the planning for continuity of care by
 - ◆ co-ordinating the delivery of “futures planning” workshops for ageing carers across the Western Metropolitan Region and
 - ◆ assisting ageing carers in their caring role by linking them to existing support systems including respite services, peer support and financial assistance
- ◆ provide intensive support to first time respite users
- ◆ link with the aged care system where appropriate for carers' own aged care needs
- ◆ collaborate with the disability service system, ethno-specific and Aboriginal and Torres Strait Islander agencies; the aged care system and the mental health system
- ◆ organise and co-ordinate a specific event or series of events (such as a carer retreat) from which friendships may evolve, and facilitate and support ongoing peer contact such as a carer support group.

Project management

The project worker will work as a member of the Disability Team and will take part in team and stream (staff) meetings unless otherwise agreed with Manager.

The worker will consult as a peer with other members of the team but will report to the Manager, Carer Support Services.

The program will be resourced by a reference group, and it is hoped that this group will comprise representatives from Care Connect and David House / WiN Support Services and the Carers Victoria Disability Policy Worker.

As an adjunct to the reference group, the existing robust regional and subregional networks will also resource the program.

Relationship to existing services

The project will connect carers with all relevant services including those operating from the CCRC (particularly those resulting from the recent CCRC expansion funding) rather than attract a caseload. For all program activities, the CCRC will organise and generally pay for respite as needed.

Project Timelines

Phase one – 8 weeks

Service mapping exercise, which will then indicate particular areas of need and generate a complementary approach to meeting the needs of carers.

Phase two – 38 weeks

Undertaking project objectives

Phase three – 6 weeks

Evaluation and review

The worker will develop and undertake **evaluation** of the project to include

Quantitative:

- ◆ the number of "Futures Planning" sessions held
- ◆ the number of carers attending
- ◆ the number of first time respite episodes planned
- ◆ the number of referrals of target group carers
- ◆ the number of carer support groups or other group activities initiated

Qualitative:

- ◆ assessment of evaluations completed by carers after each of the "Futures Planning" sessions
- ◆ assessment of feedback from carers after first time respite experiences

The worker will co-ordinate a consultative **review** of the project by the Disability Team, the Manager and the reference group. This review will assess the value of the project and will plan for any ongoing work that resources will allow.





Appendix 2

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Appendix 3

Reference Group Members

Patrice Evans, Acting Manager Disability Partnerships and Service Planning, North and West Metropolitan Region, Department of Human Services

Julie Kun, Client Services Manager, replaced by Robyn Close, Assistant Manager, Care Connect

Annie Grant, Service Development Manager, David House Adult Training Support Service

Deb Carrin, Senior Clinician, South West Area Mental Health Service

Cathy Tzoulis, Carer Support Worker, CCRC/CLW

Shirley Hynes, Disability Policy Worker, Carers Victoria

Janet Shaw, Manager, CCRC/CLW

Jill Cameron, Project Worker, CCRC/CLW





Appendix 4

Local Agencies consulted

Disability Client Services, Department of Human Services (team meeting of 16 people)

Care Connect, Client Service Manager: Julie Kun

SCOPE, Respite Manager: Jane Charles

ISIS Primary Care, ABI Program: Nola McPhee

Western Leisure Care: Jana Kulik

Moonee Valley Council Social Worker: Claudio Tine

North West Aged Care Assessment Service: Jill Taylor





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