



Gippsland Carers Association Inc

Regional Carers Support
Network

Strategy & Funding Proposal
Feb 2013

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Appendix 1

The Business Case for Carer Support

1. Executive Summary

This Regional Carer Support Network Strategy and Funding proposal developed by Gippsland Carers Association Inc. (GCA Inc.) seeks support for three years for an establishment/demonstration project for a Regional Carer Support Network. The proposal demonstrates the need for grass roots support and advocacy for unpaid family carers and aims to prevent a crisis of care in Gippsland. It details how caring for carers can play an important role in supporting those with disabilities, aged frailty and chronic ill-health and adds significant value to a sustainable health and community care system in the region.

The proposal seeks funding of approximately \$1.2M over 3 years subsidised by GCA Inc.

This proposal represents what we believe to be an Australian First. The establishment of a regional carer support network for unpaid family carers which is inclusive of all carers. Where other carer organisations act as funded service providers, or are carer adjuncts to services for people with particular conditions and disabilities, this network will focus on carers themselves- their needs, rights, aspirations and wellbeing.

It will form a partnership between a rural carer organisation, the Gippsland Carers Association Inc. (GCA), and Federation University's Department of Rural and Indigenous Health (FUDRIH) and relevant service providers where appropriate.

It challenges often city- centric views about leadership and innovation, Good things can be initiated in the regions! It aims to be an exemplar for carer support across the state. It seeks funding for a three year establishment/ demonstration project which will be fully evaluated.

Background

In Australia, unpaid family carers provide 93% of all disability accommodation and personal care services nationally and in doing so save the Australian community more than \$40.9 billion annually. Equally, families provide in-home care to frail elderly citizens and those with chronic health issues significantly reducing the need for funded out-of-home care for thousands. Despite this, unpaid family carers lack the rights, voice and support afforded to those with a disability able to access self-advocacy, service providers and the aged care funded accommodation sector. Carers are left out of the policy and planning processes which impact on their lives, whilst their caring roles negatively affect their health, well-being, financial security, and life chances.

Gippsland Carers Association Inc. is committed to changing the situation in which carers currently find themselves. GCA has a proud history of action, leadership and innovation. However, we know that support for carers needs action and resources beyond our capacity as a totally volunteer organisation. We are supported in this view by carers across the nation, and by Carers Australia.

"Carers Australia recognises the significant contribution of grassroots organisations such as Gippsland Carers Association in assisting Carers at the local level. It hopes that, in partnership with these organisations, the needs of Carers, particularly those most isolated might be better understood and responded to in a holistic and responsive way. It supports initiatives that bring Carers together and responds to their needs and concerns".

Tim Moore, President Carers Australia

Gippsland Carers Association was formed in 1997 as a self-help and advocacy group to support and assist unpaid family carers in Gippsland. Since then it has grown to provide peer support, skills development, information, education, and links to services and assistance to carers. It advocates vigorously for a better deal for carers and enjoys a national reputation as an advocate for carers, until 2010, on a totally volunteer basis.

This document provides details of a proposal for the establishment of a regional carer support network establishment/demonstration project.

In a truly exciting development, the then Monash Department of Rural and Indigenous Health (MUDRIH), [now Federation University] actively supported the GCA in submitting this proposal to Governments.

The project is supported by Latrobe City Council, VLGA, The Committee for Gippsland, the Victorian CWA and a significant number of support organisations, both local and state-wide.

This document sets out the vision and plans held by Gippsland Carers Association Inc. to drive the transition from a largely volunteer information, education, and assistance with links to services and peer advocacy centred in Morwell; to a funded fully operational regional carer support network.

Project Outcomes:

The **outcomes** pursued by the Project are:

- that carers are supported in their role at the grass roots level.
- to improve the care of people who are frail, aged, have a disability or chronic illness by providing support, information, education, links to services and peer advocacy
- to break down the social isolation of carers
- to improve the health and well-being of carers

Project Objectives:

The objectives of the project are to establish a regional network to:

- provide a grass roots, outreach information service to give practical help (such as form filling, accessing services and support), and accurate referral information to carers
- advocate on behalf of individual carers and work with other services to ensure the needs and rights of carers are being met
- develop the Carers Place in Morwell as a full-time, five days a week resource
- develop web based resources and investigate the potential of technology to support carers
- develop carer support groups particularly those targeting "hidden carers" who may live in remote rural areas
- facilitate education and information sessions for carers and empowerment to help themselves
- develop and maintain appropriate links and networks with other services in Gippsland and liaise where appropriate with relevant levels of government, service providers and carer peak organisations
- evaluate the effectiveness of a range of support services.

Project Resourcing

The project requires resources to support a fully funded program comprising a full-time co-ordinator, two outreach project workers [mentors], a part-time administrative/clerical worker and funding to assist the delivery of support groups, in-home carer help, website maintenance, and expenses associated with travel requirements to deliver services in a rural setting.

Service Model

We are committed to delivering a multi-component service (information, education, links to services, support, outreach to the family home and advocacy) to carers using peer support and mentoring as a delivery mechanism, with systemic advocacy and community education on carer issues, a key factor for sustainability.

Gippsland Carers Association Inc. AIN A0035748T - PO Box 937, MOE VIC 3825 – Phone: 035127 1904
Email: gippscarer@vic.australis.com.au website: www.gippslandcarers.org

[Monash] now Federation University Department of Rural and Indigenous Health (FUDRIH) Partnership

The project development was supported by Federation University's Department of Rural and Indigenous Health (FUDRIH). This involvement may include representation on the project committee, the development of a framework to evaluate the effectiveness of the project, access to expertise, [including from a research team currently investigating the issues affecting carers supporting frail aged adults] and input to all reporting processes.

Evaluation

Gippsland Carers Association is committed to rigorous evaluation. It is aware that current research into what actually works in relation to carer support is scarce, and understands that this project will be ground breaking.

The organisation's philosophy is one which values education, advocacy, empowerment and independence. This informs the approach to evaluation.

A partnership with FUDRIH will ensure the project is thoroughly evaluated. Measurement and evaluation approaches will be built into the detailed project development strategies. An action research approach to evaluation will ensure a capacity to make improvements along the way and to capture the voices of carers in the evaluation process.

Conclusion

The GCA Inc. initiative proposes an effective model for providing support to unpaid family carers in the Gippsland region. It is informed by the experience of carers who understand the day to day demands of the caring role and have arrived at proposed solutions to the alarming problems faced by carers.

In Gippsland, there are about 27, 000 caring families. There are more than 13, 000 people who are primary carers of people with a dependent disability/frailty. The funding proposal for approximately \$1.5m over 3 years provides a modest opportunity for a sharing of the responsibility for disability care beyond almost total reliance upon unsupported family carers.

The timing of this project is fortuitous, as it coincides with activity related to development of the NDIS, and its roll out on a regional basis. A Gippsland Regional Carer Support Network will provide an example of carer support aligned with NDIS regions, philosophy and intent.

This will allow for a full review of the KPI's for governments to consider a full roll-out for Regional Carer Support Networks State and nation-wide.

This makes political and economic sense as unpaid carers contribute over \$42billion to the annual national budget bottom line and their ongoing dedication is irreplaceable.

2. Introduction

This proposal represents what we believe to be an Australian First. The establishment of a regional carer support network for unpaid family carers which is inclusive of all carers. Where other carer organisations act as funded service providers, or are carer adjuncts to services for people with particular conditions and disabilities, this network will focus on carers themselves- their needs, rights, aspirations and wellbeing.

It is a partnership between a rural carer organisation-Gippsland Carers Association Inc. (GCA) and the Monash Department of Rural and Indigenous Health (MUDRIH).

It challenges often city- centric views about leadership and innovation. Good things can be initiated in the regions! It also acknowledges the value of the lived experience of carers and peer support in the design and delivery of the project. It aims to be an exemplar for carer support across the state. It seeks funding for a three year establishment project which will be fully evaluated.

Gippsland Carers Association Inc. (GCA) was formed in 1997 as a self- help and advocacy group to support and assist unpaid family carers in Gippsland. Since then it has grown to provide peer support, skills development, information, education, and links to services and assistance to carers. It advocates vigorously for a better deal for carers and enjoys a national reputation as an advocate for carers.

This document provides details of a proposal for the establishment of a regional carer support network pilot program. The Monash/Federation University Department of Rural and Indigenous Health (FUDRIH) supports the GCA in submitting this proposal. The project proposal is also supported by Latrobe City Council, VGLA, The Committee for Gippsland, and a significant number of support organisations including Carers Australia.

The document sets out the vision and plans held by Gippsland Carers Association Inc. to drive the transition from a largely volunteer information, education, assistance, links to services, and advocacy organisation centred in Morwell to a funded regional carer support network.

This transition has as its foundation, years of work on the part of GCA to highlight the need for grass roots support for carers. After endless reports identifying the toxic results of lack of information, lack of access to benefits, compromised carer physical and mental health and their social isolation, this project will tackle the issue in a practical way.

A funded regional carer support network seeks to connect carers to existing services, provide practical help to carers and highlight service gaps.

This project will contribute to advancing the cause of immediate support for carers while continuing to highlight the alarming systemic issues which are that, without substantial change and significant support across the nation ... *'We have a 'death spiral' in the current system, with ageing carers unable to cope, giving up their adult children to expensive taxpayer-funded care, leading to reduced respite support, and putting more strain on the remaining carers. Not providing adequate support now requires increased dollars later.* (Associate Commissioner, Australian Productivity Commission, John Walsh, the Disability Care and Support, Draft Report, February, 2011¹)

We believe that unpaid family carers have the right to expect funded support services as a mutual obligation, proportionate to the contribution they make to society – the general community benefits from their substantial contribution of over \$40 billion nationally

¹ Productivity Commission (2011) Media Release - Disability Care and Support, Draft Report, 28 February, 2011
<http://www.pc.gov.au/projects/inquiry/disability-support/draft/media-release>

3. Vision, Mission, and Strategic Focus

Our Mission

To improve the quality of life for unpaid family carers of people with disabilities, aged frailty or chronic health issues and for those for whom we care

Our vision

That carers have the same rights and life possibilities as the broader community and that, as providers of 93% of disability accommodation and care services nationally, carers have the right to have government recognition, input to policy and planning, services and support and the opportunity to participate in the direction of their own lives

Our Strategic Focus

Four key themes drive our strategic plan:

- Support
- Information and Assistance
- Peer Advocacy
- Resourcing and Growth

This means expanding our capacity to:

- support all carers in Gippsland with a five day a week fully funded service offering peer support, empowerment strategies and outreach services,
- provide accurate information to carers, support carers to access services and benefits and educate the community on the role of family carers
- provide advocacy, representation and policy development for equity and support for diverse carer demographics
- operate a sustainable organisation which has sufficient resources to meet the growing and changing needs of carers in the region

4. Evidence of Need

The need for greater support for unpaid family carers is indisputable. In Gippsland and nationally, what carers need are fully funded grass roots, accessible support, information and assistance services. The scope of the need is beyond the capacity of a part-time volunteer service.

The need is urgent:

- support and service needs to reach more carers- less than 50% of carers are known to have any contact with services due to isolation and lack of knowledge of available services²
- a substantial minority of carers (one in five) who have no assistance from other people in caring for the person or people with a disability.³

² ABS Survey of Disability, Ageing and Carers, 2003.

³ Australian Institute of Family Studies (2009) The Nature and Impact of caring for Family Members with a Disability in Australia

- the wellbeing of many carers is in precarious state. Carers have the lowest collective wellbeing of any group and have an average rating classified as moderate depression and are highly likely to carry injury associated with reduced wellbeing'.⁴
- the compounding social factors contributing to poor mental health include isolation, rurality, limited economic and educational opportunities, the absence of supportive networks and environments, and limited access to needed health services, which sadly describes the situation of many Gippsland carers.

The need is growing:

- demographic changes, medical improvements which result in longer life expectancy, lack of funding for appropriate accommodation mean there are many profoundly disabled adults being cared for by unpaid family carers
- stress on relationships and carer health and well-being all mean that many profoundly disabled adults live with ageing parents, single parents or carers who experience poor mental and or physical health.
- family carers are isolated in their homes- an outreach service will break down the isolation.
- many family carers live in poverty because caring stops access to paid work (57% of carers are of workforce age), access to carer payments is means tested, and there are no long day care services for older children and adults with dependent disabilities.
- The advent of the NDIS will positively impact on numbers of carers; however, the Productivity Commission have made it quite plain that the NDIS "will not work without the ongoing support and commitment of unpaid family carers." In addition, there are many carers of people who will not meet NDIS criteria. The need for a regional carer support network clearly remains.

⁴ Australian Unity Wellbeing Index, Carer Health and Wellbeing, 2007.

5. Meeting Gippsland Carers Needs

Gippsland has a population of 259, 063. Some 51,800 people - 20% of the population in Gippsland, have a disability of some kind. There are 27,000 unpaid family carers. Carers are providing personal care and accommodation to 22,500 people who have a disability, chronic condition, terminal illness or mental illness, or who are frail aged requiring care. 20% of carers are aged 65 years and over. 7,962 of carers earn less than \$250 per week. The employment rate of carers is 62%.

Table 1 provides a demographic profile of Gippsland carers and people who require assistance.

Table 1: Gippsland carers and the people for whom they care (2010)

	Bass Coast	Baw Baw	East Gippsland	LaTrobe	South Gippsland	Wellington	Gippsland Total
TOTAL POPULATION	30800	41200	44000	72900	27400	42700	259063
No of Carers	3500	4000	4700	7200	2900	4300	26631
Carers Aged 15-19	90(3%)	150(4%)	130(3%)	200(3%)	70 (2%)	160 (4%)	431 (1.6%)
Carers Aged 20-64	2530(72%)	3140(78%)	2470(73%)	5270(79%)	2200(76%)	3370(78%)	20874(78%)
Carers Aged 65+	880(25%)	710(18%)	1100(24%)	1260(18%)	630 (22%)	770 (18%)	5326 (20%)
No of people requiring assistance	2,800	3000	3600	7500	1900	3600	22523
% of people requiring assistance Aged 65+	1990(71%)	2130(70%)	2450(68%)	5340(71%)	1350(70%)	2510(69%)	15766(70%)

Reference: National Respite for Carers Program Demographic Analysis of Care Needs and Service (2010)

Gippsland is a region in Victoria which has a relatively high level of socio-economic disadvantage. It has a proportionately high level of residents who are over 65 and this level is expected to increase sharply. It also has a high level of indigenous residents, more than double the Victorian average. Currently the region is deemed to have a high level of unmet health and community needs. The demand for services for the aged and disabled is expected to grow substantially.

The broader business case and description of trends and issues relating to carer support are set out in Appendix 1.

6. GCA Inc. - Organisational Capacity

6.1 Overview

The achievements and growth of GCA Inc. is testament to its capacity to create and maintain a Regional Carers Support Network. GCA Inc. is a dynamic, forward looking carer support and advocacy organisation and has the capacity to deliver the expansion of service this proposal determines.

Since 1997, it has provided services, education and information to thousands of carers in the region. Its quarterly newsletter The Gippsland Carer has a wide circulation. It runs bi-annual forums with education, information and empowerment as the key areas of focus. It has a highly visible community presence through its shop front premises – the Carers' Place – in the Morwell shopping centre.

It serves the local carer community, and seeks to influence the provision of services for the people for whom they care.

6.2 Current activities and services

Delivering services, information and education to carers, which include:

- Carers Place – shop front centre open three days a week
- Information and assistance
- Twenty-four hour telephone assistance provided by Committee of Management members
- Quarterly newsletter The Gippsland Carer
- Bi-annual forums
- Web-site www.gippslandcarers.org
- Support groups

Balancing local services with strong advocacy at state and federal level, such as:

- Presenting a plethora of Submissions to Government Inquiries over many years
- Appearing at Public Hearings - state and federal
- Co-founding and acting as auspice body for the National Carers Coalition (NCC)
- Developing Nationwide links to volunteer carer support groups
- Developing relationships with service providers
- Involvement in National carer campaigns for a fairer deal for caring families caused a Senate Inquiry to be held into the operations and funding of the Commonwealth, State and Territories Disability Agreement (CSTDA)
- The production of a policy document on the need to introduce Population – based Benchmark Funding to disability services to remove age discrimination and put disability services on a level playing ground with aged services.
- Conducting forums to give carers input to the Victorian Disability Accommodation Inquiry, Review of Guardianship and Administration Regulations and Supported accommodation choices review.
- Federal Government NDIS Inquiry and Hearings, Petitions Committee Hearing, Carers Strategy, Aged Care Inquiry

Note: GCA has placed this proposal before both State and Federal Governments on an ongoing basis; including the current Victorian Government and the current Federal Minister responsible for carers Senator Mitch Fifield, without success.

7. Regional Carer Support Network – Project Plan

This section sets out the project details; it identifies resourcing requirements, the rationale for the chosen service model, and the project management arrangements including the scope of the partnership arrangement with MUDRIH.

7.1 Project Outcomes:

The **outcomes** pursued by the Project are:

- That carers are supported in their role.
- To improve the care of people who are frail, aged, have a disability or chronic illness through providing support, information, and education services
- To break down the social isolation of carers
- To improve the health and well-being of carers

7.2 Project Objectives:

To provide resources to establish a regional network to:

- Transform Carers Place to a 5 day per week service access centre
- provide support through a grass roots, outreach information service to provide practical help and accurate referral advice to carers
- advocate on behalf of individual carers and work with other services to ensure the rights of carers are being met
- develop resources and investigate the potential of technology to support carers
- develop carer support groups particularly those targeting "hidden carers" who may live in remote rural areas
- facilitate education and information sessions for carers and the general community

7.3 Outputs- how would the service work?

The service will:

1. Develop approaches in each LGA in the Gippsland region to encourage carers to become members/make contact
2. Develop a range of information/communication strategies to publicise existing carer support services and resources
3. Assist carers to access appropriate information
4. Develop an outreach support service to provide carer assistance and support carers to enable them to make use of support groups and other services.
5. Provide a grass roots, accessible information and peer support and advocacy service to provide practical help (such as form filling, accessing services, emotional and social support, and solving problems),
6. Ensure access to advice, counselling and support
7. Advocate on behalf of individual carers and work with other services to ensure the needs of carers are being met
8. Develop the Carers Place in Morwell as a full-time, five days a week resource.
9. Develop a range of resources including web based resources and investigate the potential of technology to support carers
10. Expand and grow the Gippsland Carer newsletter , Develop carer support services and support groups, particularly those targeting "hidden carers" and carers with high needs who may live in remote rural areas.
11. Develop appropriate links and networks with other services in Gippsland and liaise where appropriate with relevant levels of government, service providers and carer peak organisations

7.4 Project Resourcing

The project requires resources to support a fully funded program comprising a full-time co-ordinator, two outreach project workers/mentors, a part-time administrative/clerical worker and funding to ensure the delivery of support groups, website maintenance, expenses associated with travel requirement to deliver services in a vast rural setting.

7.5 Staffing

The proposed staffing requirements are:

Figure 1: Staffing levels

Positions	FTE
Co-ordinator	1.0
Project workers (Carer Mentors)	2.0
Administration/Reception	.05
Total	3.5

Figure 2: Financials

Funding requirements	Year 1	Year 2	Year 3
Salaries and on-costs			
Coordinator	75,000	78,000	81,120
2 x Outreach Workers (Carer Mentors)	126,464	131,523	136,784
1 x Full-time Clerical	57,304	59,596	62,480
On costs payroll/employment expenses/ Superannuation & Worksafe) (15%)	38,815	40,367	42,057
Total			
Staff Training and Supervision (5%)	14,229	14,762	15,323
Recruitment expenses	4,000		
Administration (utilities, Internet, Office Expenses, Telephone. Insurances)	11,900	12,495	13,090
Equipment Notebooks/Mobile Phones	5,000		
Rental * (+2.3CPI)	45,000	46,035	47,093
Project Development Costs (Policy , Information/resource handbooks, Website, Printing, Support Group costs, Community Education, Workshops)	45,000	47,250	49,500
Travel and accommodation	6,200	6,300	6,400
Purchase 2 Motor vehicles **	52,000		
Vehicle Running costs (as per RACV)	44,232	44,232	44,232
Evaluation /Documentation	30,000	30,000	30,000
Expenditure Annual Total	\$555,144	\$510,560	\$528,079
Less Income - Rental expenses- and \$ Fundraising	44,000	44,637	19,884
Total Required	\$511,144	\$465,923	\$508,195

*Donation secures part rental

** Project requires 2 cars for outreach workers – 1 car has been purchase- partly funded by Newman's Own Foundation grant

GCA Inc will provide additional resources to this project which include:

- Overall Governance and irreplaceable experience of grass roots caring issues
- Support to the Project Evaluation Committee and Staff
- Venue – rental of Carers Place is secured
- General Office equipment and general expenses
- High Profile access to community and media
- Other Regions will need to fully fund a project

This level of funding presumes a continued substantial volunteer effort and fundraising particularly in relation to advocacy, community education and the development of innovative peer support initiatives. We have maintained for many years that a fully funded regional support network would require approximately \$650,000 pa.

7.7 Service Model

There is widespread acceptance that services in rural regions need to be different from those in metropolitan areas. There is also acceptance (not matched with resourcing or policy recognition) that carers needs are separate from those of the people for whom they care. Carers are well placed to support other carers navigate system and personal issues.

Academic research suggest that little is known about the effective 'dose' of carer support interventions or the best time for their delivery and very few studies appear to consider the fit between carers' stated or assessed needs and the model of service provided.⁵

Available **research** and the experience of GCA have identified that carer support needs to address the following:

- Information is key- it has to be timely, accessible and pitched at the level individual carers can understand
- Systems are complex and hard to navigate – firsthand experience shared by other carers is invaluable
- Form filling is challenging and sometimes information is incomplete or just plain wrong
- Informal and one on one support is required to assist some carers to have the confidence to access services and to participate in group or more organised settings
- Lack of knowledge is a significant barrier – if a carer doesn't know what is available, how can they ask?

These are the issues which Gippsland Carers Association has grappled with for over a decade. Through research, discussions at regular carer forums, from the experience of carer members and through analysing the issues carers who seek assistance from GCA have presented, the proposed model of service has been formulated.

We are committed to delivering a multi-component service (information, education, support, and outreach and advocacy) using peer support as a delivery mechanism.

We intend to have the pre-requisite that staff members have strong experience/knowledge of the caring role.

The following service model illustrates our capacity to deliver the service we propose.

⁵ Eagar K et al. (2007) **Effective Caring: a synthesis of the international evidence on carer needs and interventions**. Centre for Health Service Development, University of Wollongong.

Figure 2: Proposed Service Model

Service Model		
Carers		System & Resourcing
Information & Education	Support	Advocacy
		Links to Services
		Mentoring
Carers Place	Carers Place	Forums/one to one
Newsletter	Resource Directory	Newsletter
Resource Directory	Website	Website
Website	Phone Help Line	Partnerships
Phone Help line	Email Help line	Representation
Email Help line	Support Groups	Public Education
Forums	Support Group Facilitation Training	Media /PR
	Outreach	Submissions

7.8 Monash University Department of Rural and Indigenous Health (MUDRIH) Partnership

The project will be supported by Monash University Department of Rural and Indigenous Health (MUDRIH). This involvement will include representation on the project committee, the development of a framework to evaluate the effectiveness of the initial phase of the project, and access to expertise, including from a research team currently investigating the issues affecting carers supporting frail aged adults.

7.9 Establishment of the Service

Over the next three years, we will work to make the transition to a regional network with paid staff and volunteers and to fully evaluate the service. We will develop an appropriate framework – largely based on community development and peer support approaches – to develop an effective carer support system in Gippsland.

MUDRIH expertise in the further development of models of service, access to the expertise of the Key Centre for Excellence in Peer Support and the knowledge of carers themselves will inform the development of the service.

This project represents far more than an extension of GCA's current services. It seeks to understand how unpaid family carers' needs for social support, access to information and services, enhanced mental and physical well-being and, for some, access to paid work can be met. It seeks to work out ways to reach "hidden carers"

7.10 Risk Management

There is attention to the issues of risk management in the development of a peer support and outreach service. Relevant research and consultation has identified useful models and the offer from Mirabel Foundation to assist in the development of a comprehensive risk management strategy will be part of the early implementation stage.

7.11 Governance

The project will be managed by a Project Management Committee comprising:

Name	Background
Jean Tops	President and Founder Gippsland Carers Association Inc. Carer for 42 years Chair of Disability Accommodation NGO for 8 years/member establishment COM Lifelong advocate for caring families Founding member National Carers Coalition Editor of The Gippsland Carer and author of a range of submissions, articles and reports. Media commentator
Patricia Nalder	Gippsland Carers Association Volunteer Ex- CEO Lifeline Gippsland Expertise in volunteerism, training, community development and support, mental health, and fundraising Involvement with a range of organizations operating in the areas of mental health and primary care
John Foster	Gippsland Carers Association Committee of Management Member GCA volunteer Former HR practitioner and University Tutor Author of a range of articles on social justice and carer issues
Dr Anske Robinson	Research Fellow. Monash/Fed University Department of Rural and Indigenous Health Expertise in research methods and wellbeing of older adults in the community
Molly Burley	Lecturer, Monash/Fed University Department of Rural and Indigenous Health. Expertise in rural health management and inter-professional learning across health disciplines

7.12 Evaluation

Gippsland Carers Association is committed to rigorous evaluation. It is aware that current research into what actually works in relation to carer support is scarce, and understands that this project will be ground breaking.

The organisation's philosophy is one which values education, advocacy, empowerment and independence. This informs the approach to evaluation.

A partnership with FUDRIH will ensure the project is thoroughly evaluated. Measurement and evaluation approaches will be built into the detailed project development strategies. The project design provides for integrated evaluation – a reference group comprising representatives of the Association, Carers, expert volunteers and local service providers, together with nominees from Monash/Fed University Gippsland will identify and implement suitable evaluation methods.

An action research methodology is proposed, to enable agile service improvements along the way, and to capture the views of carers.

At a minimum, it is anticipated that the evaluation would involve:

- Measuring carer satisfaction and service utilisation
- Case studies /vignettes
- Effectiveness evaluation- accounting, financial and information systems, using a common metric across the program (for example, cost per individual supported) and comparisons with metrics across the disability advocacy field
- Evaluation techniques will form part of staff training and assessment

GCA is aware of the need for robust information and insight to support the development of carer support strategies across the state. There will be a high level of attention to accessible evidence presentation, evaluation and documentation.

Future Funding and Support Strategy

We are of the view that sustainability is about capacity building, effective planning and building positive relationships. This forms the foundation on which to build a funding strategy.

GCA has recently engaged in a capacity building exercise and improved its strategic planning capacity. It has enhanced its financial situation has attracted funding from the philanthropic sector. Much relationship building on the part of the President GCA has resulted in strong support from local Members of Parliament; the state government has provided \$100,000 over next 4 years. A Committee of Management decision was made to apply the allocation in this current year to the employment of a part- time administrative/reception worker

GCA has strong support from the LaTrobe Council, the Victorian Country Women's Association and a range of Government, Carer and Community organisations at the national, state and regional level.

GCA has developed a comprehensive funding strategy to ensure future sustainability. Funding for the next 3 years to establish the Regional Carer Network will we feel sure, be followed by secure funding into the future.

Carer issues cross the program areas of a number of government departments. The strategy comprises seeking funding from the following government, philanthropic, corporate sources:

Funding Source	In particular:
Commonwealth Government	FACSLIA Department of Health and Ageing Social Inclusion Agenda Support roll out of NDIS
State Government	Seek pre-election commitment from local Members of Parliament DHS Department of Health (inc Mental Health) DPDC Regional Development Victoria
Local Government	6 LGA's in Gippsland
Regional Development	Gippsland Strategic Plan Community Strengthening Contact with Committee for Gippsland
Philanthropy	Philanthropic Trusts Funding for special projects
Corporate	Contact with range of organizations Address to Gippsland Employer groups Corporate Membership category
Forums Membership of GCA	In 2011 the LaTrobe Community Health Carer Services and Carers Vic supported 2 GCA Regional Forums Explore potential to increase support from such sources
Community Organisations	Potential specialist project funding

Much work has been done, in developing relationships and writing submissions, However, the full realization of the funding strategy requires the involvement of a paid co-ordinator.

Following the appointment of a full time coordinator, the further development of the funding strategy can proceed.

8. Conclusion

Researchers have crunched the numbers so that they know the extent of the commitment of family carers and they are aware of the financial, medical, social and emotional costs borne by such families, but they do not have access to the impact on a case by case basis. Nor, is there real insight into solutions.

This project will put those case by case impacts, and creative and innovative solutions squarely before decision-makers/families. The most compelling of the reasons for establishing a regional support network is that it will provide an exemplar for other regions especially at this time when plans are being formulated to introduce the National Disability Insurance Scheme and to reform the aged care residential sector.

Ongoing commitment to a fully funded regional support network is needed to ensure that carers in the region have sufficient support to continue to care for some of society's most vulnerable people- people with a dependent severe or profound disability- and to continue to provide their accommodation and personal care.

As Associate Commissioner, Australian Productivity Commission, John Walsh said in the Disability Care and Support, Draft Report, February, 2011. 'We have a 'death spiral' in the current system, with ageing carers unable to cope, giving up their adult children to expensive taxpayer-funded care, leading to reduced respite support, and putting more strain on the remaining carers. Not providing adequate support now requires increased dollars later.

The GCA Inc initiative delivers an effective model for providing support to unpaid family carers in the Gippsland region. It is informed by the experience of carers who understand the day to day demands of the caring role and have arrived at proposed solutions to the alarming problems faced by carers.

In Gippsland, there are about 27,000 caring families. There are more than 13,000 people who are primary carers of people with a severe/profound dependent disability. The funding proposal for approximately \$1.5 m over 3 years provides a modest opportunity for a sharing of the responsibility for disability care beyond family carers.

The timing of this proposed project is fortuitous, as it coincides with activity related to development of the NDIS, and its roll out on a regional basis. A Gippsland Regional Carer Network will provide an example of carer support aligned with NDIS regions. The project also coincides with reform of the aged care and mental health sectors all of which rely heavily on ongoing family and unpaid carer involvement.

Appendix 1

The Business case⁶ for Carer Support

Apart from an equity argument, there is a compelling business, economic, political and social policy case for supporting unpaid family carers.

Well – being and Social Inclusion drivers of Gippsland Regional Development

The Gippsland Regional Plan (2010)⁷ identifies well- being and social inclusion as key development drivers. It notes that investment and planning will be required to support subregional health services meet the growing needs of the community. The continued development and expansion of community based aged care by local and subregional health services will be required to support the increasing aged population to remain within their community

National Disability Insurance Scheme (NDIS)

The introduction of the NDIS offers positive support and choice for those who come under its aegis, however, it also poses the risk of a reduced focus on systemic and structural issues as funds are largely only sufficient to support individuals, and service quality standards if it 'market driven standards" prevail. This will mean the need for systemic advocacy and for support for some people with a disability and their families and carers as they have to shop around for service suitability and quality.

This project is timely in that it provides an opportunity to develop a service to support carers as the NDIS is being rolled out. That the NDIS is to be implemented on a regional basis gives further support to the value of this project.

Sustainability

No future health, mental health, aged, disability or community care systems will be able to respond to the changing demographics and health needs, clinical practices and societal influences in the long term without carers. Carer support has the immediate benefit of reducing pressure on a range of services, including hospital admission and length of hospital stays. Breakdown of unpaid family caring has massive impact on the quality and cost of care. Further, if carers are not healthy and do not have appropriate support and access to the long-term economic and social burden for government will be extensive.

Carer Supply

Trends indicate a declining ratio of carers to people requiring care due to demographic, economic and social changes which mean that there is a decreasing number of people willing and able to provide care coupled with an increasing number of people requiring care.

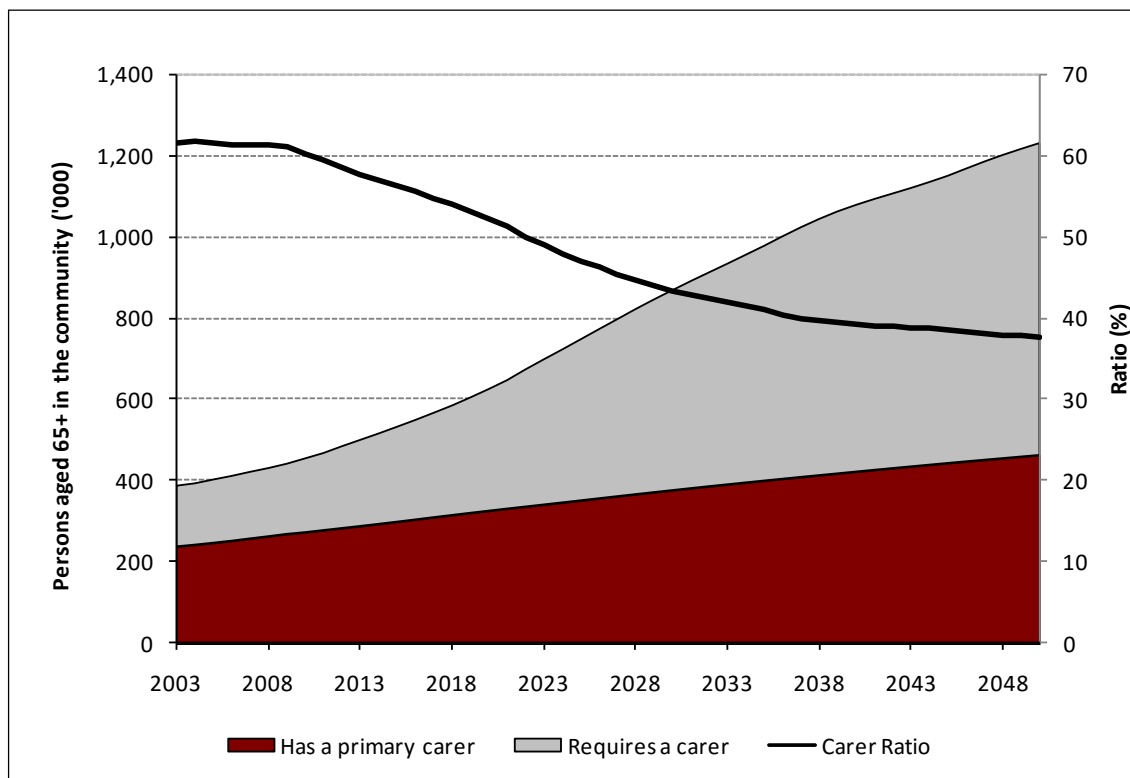
As Chart i shows, the 'carer ratio', of primary carers to older people with a disability, is projected to fall from 60% now to under 40% by mid-century reflecting that demand for informal care will substantially outstrip supply.

⁶ Access Economics (2010), The economic value of informal care in 2010, Access Economics Pty Ltd

⁷ Regional Development Victoria, Gippsland Regional Plan 2010

http://www.rdv.vic.gov.au/__data/assets/pdf_file/0011/67844/GRP_V10.4.1_pp1-111.pdf

Chart i - Projected demand and supply of informal carers



Source: Access Economics calculations.

Replacement Value

The replacement valuation reveals the resources that would need to be diverted each year from the formal economy to replace the work done by informal carers, were their services no longer available. If all hours of informal care were replaced with services purchased from formal care providers and provided in the home, the replacement value would be \$42.0 billion (equivalent to 3.2% of GDP and 60% of other formal health care). This figure is 33% higher than in 2005.

The growth in the value of informal care derives largely from demographic ageing – which is increasing the number of Australians who require and receive care – together with growth in the replacement cost of care from \$25 per hour on average in 2005 to \$31 per hour today.

Even using the most conservative 'opportunity cost' method, the value of informal care is around \$6.5 billion per annum. This is about the same value as all high-end residential aged care paid for by the Australian Government (0.5% GDP).

Informal carers provide 1.32 billion hours of care each year, and represent a precious economic resource in an age of growing health and aged care workforce shortage.

The valuable contribution of Australia's 2.9 million carers, which enables their loved ones to remain at home, comes at a health cost to carers themselves- the burden of caring-related conditions such as depression, stress-related illness, sleep deprivation and musculoskeletal problems is significant

Workplace Participation

This burden extends to considerable forfeiture of income. An estimated 129,900 carers are not employed due to their caring responsibilities (1.1% of Australia's workforce). The opportunity cost of time devoted to informal care, measured as reduction in paid employment due to caring, provides a 'lower bound' estimate of \$6.5 billion (equivalent to 0.5% of GDP and 9.5% of the value of formal health care). This measure reveals the resources that are diverted each year from production in the formal economy to informal care.

Rates of employment and labour force participation among carers are substantially lower than the Australian average, even when standardised from differing age-gender profiles.

The Contribution of Carer Support

Informal family care remains one of the lowest subsidised forms of care, and family carers remain under-resourced in terms of education, information, support and advocacy compared to paid care workers.

Investments in informal carer support have been shown to be cost effective, there is a strong case to prioritise support for carers that can delay or prevent costly institutionalisation. Such support includes provision of information and access to respite support and income support (currently 50% of carers do not access resources to which they are entitled); education and training; preventative health and mental health care and social support. This multi – component support model forms the foundation of our (GCA Inc's) proposal.

Such support for carers will help enhance the current wellbeing of carers and also contribute to carer supply, as well as meeting Australia's obligations to optimise wellbeing for the frail aged, those disadvantaged by disability, mental illness or chronic illness.

Please Note:

It is our firm belief that Regional Carer Networks are desperately needed across the whole of Australia. The cost of funding this initiative pales into insignificance when compared to the massive contributions unpaid family carers make to the national economy.

We make a strong recommendation to the Governments of Australia that there be funding budgeted to encourage the establishment of Regional Carer Networks across at least 44 Regional locations (based upon government delineations by various departments.)

The estimated cost of these networks will be around \$26million P/A based on a conservative annual costs of \$600'000 per region.

The NDIS is timed to commence its roll-out across the entire nation from 1 July 2016 and be completed by 2019-20.

Time is now critical for governments to hold fast to the irreplaceable family home based services of unpaid carers to ensure the NDIS remains viable.