

# **Regional Family Carer Support Networks**

***'the forgotten unmet need'***

## **Preamble:**

Created, and driven wholly by unpaid family Carers of people with dependent disabilities, the Gippsland Carers Association Inc (GCA) joins with thousands of Australian caring families in a common belief.

'There must be radical reform of caring family support services throughout the nation in order that long suffering families may find relief from unrelenting burdens of care for people with disabilities, handicap and frailty created by unmet support needs.'

This unmet need includes, as a matter of urgency, the need for the implementation of a fully funded Region-Based Family Carer Support Network across the nation to enhance lives and bring caring families into the mainstream.

The National Carers Coalition (NCC) together with GCA made detailed submissions to the Federal May Budget process and directly to the Minister for FaHCSIA in 07/08 and 08/09 for funded Carer Support and Advocacy Networks, but to no avail.

The NCC has its beginnings in the very public *Walk a Mile in My Shoes Campaign* commenced in the second half of 2005. The overwhelming view of families supporting the *Walk a Mile in My Shoes Log of Claims* was a call for a National Carer Networks funded by Government from the grass roots of caring **'at the Regional Level.'**

To give caring families 'on the ground support' and a 'Voice' in government policy and planning that directly affects their every day lives, thus creating a level playing field with Disability Self Advocacy, aged residential Advocacy and Service Provider Advocacy; is long overdue.

In making the submission to the Federal Government, Carers informed the Budget Policy Division that we most strongly resent the discrimination against caring families of persons with dependent disabilities for whom we provide over 93% of the cared accommodation across this nation. The National Disability Advocacy Review of 1999 and the later National Family Carers Voice Committee (set up by the then Minister for Family and Community Services) together with the 1996 Senate Inquiry into the Funding and Operations of the CSTDA all strongly recommended the funding of Disability Family Advocacy. **In 2010, nothing has changed.**

With changing policies in aged care and escalating pressure on families to also care more for the frail elderly and people with mental illness 'in-home', the issues of support for caring families is at an all time critical level.

The lack of funding to support caring families is particularly irksome to the 67% cohort of caring families of Australian adult citizens with disabilities who sit isolated in the 18 to 64 year age bracket with burgeoning unmet supported accommodation and support needs without any funded representation.

For the 51% of primary carers who are of workforce age, but prevented from accessing paid work by lack of support services in their caring role the crisis is compounded by the pressure to have both partners in the paid workforce.

**We seek to 'break the silence' on the exploitation of thousands of Australian families who do not receive a fair deal from the Australian society that owes them a debt it cannot repay.**

## THE SCOPE OF DEMAND FOR REGIONAL, FAMILY CARER SUPPORT NETWORKS

The ABS Survey of Disability Ageing and Carers 2003 provides the most clearly defined statistics on the number of families involved in unpaid care for persons with dependent disabilities. Briefly they are as follows:

- In 2003 there were 3.9million people (20% of the population) in Australia whose lives were affected by impairment, activity limitation or participation restriction in the environment in which they lived; of these, 2.6 million were aged under 65 years.
- The extent to which these disabilities affect everyday life is indicated by the presence of profound or severe activity limitation. In 2003, 6.9% of the population aged under 65 years (1,238,600 people) and 22% of those aged over 65 years (572,000) experienced such limitations, meaning they always or sometimes needed assistance with activities of self care, mobility and communication.

The Commonwealth State and Territory Disability Agreement/Disability Services-Minimum Data Set published yearly- by the AIHW identified in 2006:

- **721,700** persons with a severe or profound disability as the 'potential population' for disability support services, but the 2006 report shows that;
- **Only 37,400** persons were in receipt of an accommodation support service, of whom a small minority of just **17,087** received a supported accommodation bed in a group home, hostel, small residential or large residential facility as follows:

CSTDA Minimum Data set Numbers of persons in supported accommodation Nationwide in 2006-07

Cared Accommodation	Total – for Australia
Large Residential	3,544
Small residential	865
Hostels	404
Group Homes	12,274
Total	17,087

Furthermore; the number of persons with a disability in receipt of community access services (53,236) early intervention and therapy (41,135) and/or respite support (30,058) shows clearly how much reliance is placed upon unpaid family carers for the provision of accommodation and care support.

In 2008 there were 150,500 frail elderly persons in permanent aged care residential facilities with the vast majority of frail aged reliant upon scant community support services, family or friends. For Carers of the frail elderly there is growing pressure to provide care in-home due to the ageing of the population and pressure upon residential services.

Families are and always have been the majority providers of supported accommodation to people with dependent disabilities and frailty and the level of that support now equals more than 93%. This figure is clearly unsustainable into the future where the pressures are upon families to have both partners in the paid workforce. This means that more and more families will opt out of the continuing care role as children grow to adulthood without community based support services and ageing parents themselves require support due to failing wellbeing. (*Australia's Welfare 2005, reported that there were 202,000 primary carers of people aged under 65 years and of these 6,400 were parent carers aged 65 plus.*)

*Over 71% of all family carers were female in 2003 and carer workforce participation rates were just 39% compared to non carers 68% putting more and more families into the welfare and poverty traps created by governments failing to provide long family day care for older children and younger adults with dependent disabilities to allow carers access to paid work.*

*With increasing pressure upon families to maintain people with dependent disabilities in private homes and the failure of alternate care services to meet even urgent accommodation needs the plight of unpaid carers is set to escalate beyond a point of no return. The clear lack of grass roots support is putting unpaid family caring at extreme risk for future generations.*

## THE ROLE OF CARING FAMILIES IN POLICY & PLANNING - WE HAVE NO GRASS ROOTS VOICE

The National Carers Coalition, together with Gippsland Carers, produced a number of documents and information articles for distribution among the many caring families who joined the *Walk a Mile in My Shoes Campaign*. Amongst these documents were family carers views on age based discrimination, the exploitation of families, the imposition of one-size-fits-all supported living choices for people with disabilities, and the call for population-based benchmark funding to be introduced to failed disability services.

These discussion papers and position papers were then distributed to networks across the nation including to peak disability organizations and advocacy networks with a request that the information be passed on to families everywhere. We were shocked to receive a letter from the Victorian Disability Advocacy Network (VDAN), informing us that they would not distribute our information because they did not agree with our views.

Why we asked; did the disability advocacy networks in Victoria and NSW in particular and across the nation generally, express their collective objections to the fact that families caring for 93% of severely and profoundly dependent disabled persons wanted to have their say about unmet need? Disability Advocate bodies in particular, object to our views on 'discrimination in living choices' and accused us of wanting to have "institutions" back again. They object to families asking 'why it is possible for nursing homes, hostels, village living, cluster apartments, flats, etc to be accepted and in widespread use by the aged population of disabled persons, but not OK for disabled persons under 65 years old?'

VDAN wrote to us:-

*"While we share the "Walk a Mile" campaign's aim to obtain more resources and support for people with disabilities and their families, we have strong concerns about some of the positions your campaign presents. In particular, VDAN rejects the assertion that deinstitutionalisation was just a fad of the 1970's (Note: this was Not something we said!) and that congregate models should be a legitimate option for future housing and support for some people with disabilities. While there is a need for greater discussion about models of housing and support that match people with different support needs at different times of their lives, there is too, much evidence against a return to large scale congregate care. (Note: this was Not something, we asked for!) - Many people with disabilities can attest to the abuses and neglect that were associated with the institutional settings"..... and*

VDAN continued:

*"Given the concerns about the position you have put out in your materials, we will not be distributing your campaign materials or supporting your campaign. However, we would be happy to meet with you and your committee to discuss these concerns further and will work with and through VDAN to develop a collaborative approach.*

**Our offer to meet with representatives of VDAN was ignored.**

More recently in giving evidence to the Federal Government Inquiry into 'Better Support for Carers 2008' we drew attention to the adverse comments to the Inquiry by a National Disability Advocacy Peak Body. We said in part:

*" We draw the committee's attention to comments made in submission 845 to this Inquiry by the Australian Federation of Disability Organisations (AFDO) in particular:*

*Quote: "AFDO would like to see carers acknowledged for their contribution to society, but that acknowledgement should also include an understanding that the work of carers should actually be the work of paid professionals" unquote.*

*This is a back handed way of saying we want family carers out of the way and paid professionals in the job. This is a clear demonstration of an unacceptable anti-family culture, where carers are pitted against those they love and care for by advocacy groups with no personal care and accommodation responsibility.*

*We asked the Committee for a regionally based network to be established in order that family carers may have the support and advocacy they clearly desire, the VOICE they desperately need and a place at the policy and planning table that they have clearly earned.*

***We are still asking and still being ignored by governments who profit so handsomely from family care!***

Further evidence of anti-family sentiment is found in comments made publicly to carers in NSW when asking for better choices in accommodation services. In a response to families, a group calling themselves **Family Advocacy** included a 'mission statement' as follows:-

'Family Advocacy's mission is: "to attain positive social roles for people who have a developmental disability through the development and support of advocacy by families and by strengthening the knowledge, role and influence of the family." Their letter continues..... 'The organisation advocates on behalf of the interests of people with developmental disability through the actions of families.'" By their own mission: **'the organisation does not advocate on behalf of the interests of families.'**

The paradox of family advocacy that does not advocate for families (without whom, hundreds of thousands of dependently disabled persons would be without a roof over their heads) is indeed perplexing. Clearly no good will come of allowing this situation to continue!

Furthermore, the advent of Peak Carer Associations (Carers Australia) at the federal and state level, funded by the Commonwealth department of Health and Ageing as a resource and Information agency aimed at services and support for the aged, but morphed into a service provider with many services including staff training and direct service delivery across the spectrum, is yet another paradox.

Carers Australia now feels it has the right to claim it is the Advocacy body for all carers and says so in all its literature and website material! Yet when we look at the way that many State Carer bodies respond to grass roots carers we find they march to the beat of their own drum ignoring carers calls for regional representation and support.

The NCC received this communiqué from a NSW family carer in the lead-up to the Senate CSTDA Inquiry and it says;

*" I felt I had to write this to say thanks for supporting the right of carers to have their say. I was at a forum in NSW Parliament House on Mental Health hosted by the Democrats for carers and advocates. A woman from your group stood up and told us that the senate were holding an inquiry into the CSTDA and were calling for submissions. She was encouraging carers to write to the inquiry and telling their stories.*

*A representative from Carers NSW said that there was no need; Carers NSW would be writing one on our behalf. I was so shocked, I thought if this is what these large funded advocacy bodies do, encourage our silence, where was the hope? Are they funded to keep us mute, to keep us uninvolved in our own futures? I would have thought that their job was to widely distribute this kind of information, to encourage us to be actively involved in articulating our need for change.*

*What if I do not agree with their point of view? If a body is funded to assist us, wouldn't it do better to involve us? I thought it was more than a little off. As an exercise, I decided to check out Australian Carers websites to see if they were informing carers of the inquiry. I could find no reference to it on the 3 websites that I searched. Carers Australia, Carers NSW and Carers Victoria. I am at a loss to understand this. I looked on your (NCC) website and there it was as a link to the senate site. Thanks for the great work you are doing in trying to get the message out to care to encourage us to have our say. MM"*

Fundamentally it is wrong for a funded service provider to also claim to be an advocate for caring families. There is a direct conflict of interest in so doing. Quite clearly we are not represented by the disability advocacy sector nor, it would seem, are we represented by the aged care funded Carers Association organisations who feel they can speak for us without giving us any say. We therefore have no real voice to government save that, which we generate ourselves.

In recent times Gippsland Carers have through their diligence and networking received recognition and support from Carers Victoria for the need to have regional Carer support networks. As a consequence, the CEO, Maria Bohan has now written a letter of support for our efforts to establish a Regional Carer Support Network in Gippsland, recognizing that our argument for grass roots family support is valid and should be funded.

In a changing civil society carers do not have the same rights nor the same life possibilities as the broader community but they have the expectation that, as providers of 93% of all disability services nationally, they are entitled to recognition by government, input to policy and planning and the opportunity to participate in the direction of their own lives... This recognition will only begin to come with funded regional support networks across the nation.

## THE DISABILITY SERVICES INDUSTRY AND FAMILY CARERS

To discuss disability services is to discuss an industry that delivers an accommodation support service to a mere **4.8%** of the potential population of 721,000 persons with a severe or profound disability and community services to no more than **11.4%** of this potential population. (AIHW Disability Services Minimum Data Set 2006)

In comparison with disability services there were more than 150,000 long term residential aged care recipients in 2008, however this still reflects that the vast majority of care to the frail elderly is provided by family carers.

The critical question is raised here again, of just why it is then, that the Industry peaks and the disability advocacy peaks have so much influence over policy and planning decisions whilst families who provide accommodation and care to **93%** of dependently disabled persons are ignored altogether.

Unpaid family caring is often a lonely business that isolates Carers in the home. The ABS Survey of Disability Ageing and Carers (SDAC) 3003 found that over 50% of all carers had no contact with service provision at all. The small numbers of carers in receipt of Carer Payment and carer allowance is testament to this fact. [The AIHW reported in Australia's Welfare 2009 that just 130,700 carers received Carer Payment and 454,900 received carer allowance in 2008.]

It is little wonder then that the combination of poverty, lack of support services, stress and sheer neglect of family carers has led to the researchers claim that Carers have 'the lowest wellbeing score of any group so far tested'

'Carers have the lowest collective wellbeing of any group we have discovered. Carers have an average rating classified as moderate depression and are highly likely to carry injury associated with reduced wellbeing'. (Carer Health and Wellbeing, 2007).

It is our clear experience after 12 years of providing peer support to the Carers of Gippsland that grass roots contact with peers who understand their needs and feelings creates a pathway to inclusion within the local community and a pathway to seeking the information and support needed to enhance the life of the whole caring family.

**We earnestly beseech the Governments of Australia to right this wrong, and to provide immediate funding for the establishment of a Region-based Family Support and Advocacy Network across the nation.**

## **A REGION-BASED FAMILY CARER SUPPORT NETWORK – MODEL & BUDGET**

The Gippsland Carers Association Inc was formed in 1997 via a public meeting and unanimous call by caring families to have a voice that would 'Break the Silence on unpaid Caring' and is a splendid model for a Regional Family Support Network organisation.

The association is wholly managed by carers for carers and this peer support has proved to be a valued and respected asset to caring families in the region and beyond. The very nature of unpaid family caring means that regional support is essential to outreach help for families that are often housebound because of their role.

GCA are successful because they are formed from the grass roots of the constituency. The Association provides strong peer support, information, practical help and advocacy and is called upon to assist other regions and the NCC in establishing networks for family support and peer advocacy. GCA are limited only by the fact that they do not have any government funding to assist their fine work for families.

Members of the NCC team already work with communities and their caring families across many regions of Australia as a volunteer support and advocacy service with links to a myriad of self supporting Carer groups. We stand ready to support and assist these groups to form alliances for the establishment of Grass Roots regional networks across the nation...

We strongly recommend that Regional Family Support and Advocacy Networks are funded in a similar manner to the funded Disability Person Advocacy Networks which have grass roots organisations at the Regional Level across the nation.

Each State and Territory should be provided with a recurrently funded Regional Family Carer Network based upon the relevant Department of Human Services regional structure of each jurisdiction i.e. QLD has Ten (10) designated Regions, Victoria has Eight (8) regions, NSW has Six (6) regions along with WA and SA who also have Six (6) regions, Tasmania has Three (3) and NT has Four (4) regions whilst the ACT is One (1) region.

**The regional bodies will :**

- Establish networks with caring families across their region and offer peer support, information on services, support existing and create new local Carer support groups to encourage Carer participation in their community and advocacy as needed/requested.
- Work to establish their role at the policy and planning table along with Disability Advocates, Service Providers and Government Departments.
- Establish a Governance Committee/Board that will consist primarily of unpaid family carers of persons with a dependent disability and;
- Will be responsible to ensure that paid Carer workers are experienced in family caring or receive suitable training to ensure the peer support model continues and grows .

**Each of these regional networks will require funding for at least:**

- 3.0 EFT Family support workers
- 1.0 EFT Office Management
- 0.5 EFT Clerical assistance
- Office and Equipment establishment and recurrent costs
- Transportation
- Operating costs

**THE POPULATION BASED BENCHMARK FUNDING MODEL**

It is recommended that funding for the Carer Family Support Network be based upon a national per Carer funding formula equalized across urban and rural regions to ensure equity of access and to cover the funding required for:

- The support work to be hands-on at the Regional and sub-regional level.
- Staff Training to be paramount to ensure acceptance by families.
- The costs of access, including transport and travel costs for rural and remote regions to be offset by making every region equal for funding.
- Committee/Board support be included to ensure peer guidance to staff is available.

**THE RECURRENT FUNDING MODEL**

The formula for providing funding will be based upon the accepted number of Carers across Australia being conservatively 2.5 million and the estimated cost of delivering the Regional Carer Support Networks divided conservatively by the number of DHS regions per jurisdiction. i.e.

QLD, NSW and VIC x 8, WA and SA x 6, NT x 4, TAS x 3, ACT x 1..... Total regions = 44.  
Note: QLD with 10 designated regions and NSW with 6 regions have been equalized to provide equity.

## Per Region Cost Estimate

Cost Item	Annual Cost \$
Support Co-ordinator	65,000
Regional Project Workers x 3 @ \$45,000	135,000
Administrative/Clerical Officer .5	20,000
Salary on-costs @ 20%	44,000
Travel expenses	25,000
Support group maintenance costs \$3000 / LGA	18,000
Community education, information	12,000
Website costs	5,000
Office Equipment annual maintenance	10,000
Office Rental Costs	28,000
Operating Costs @ 12%	46,000
<b>Total Estimate per region</b>	<b>408,000</b>
<b>Total annual cost for 44 regions nation-wide</b>	<b>17,950,000</b>

Note 1. There will be a clear need to make establishment funding available for an entirely new support system to be delivered to unpaid caring families, including purchase or lease of vehicles for the Carer Project Workers.

Note 2. Since Gippsland Carers Association have offered such a service on a voluntary basis over the past 13 years, we believe we have the estimate of costs close to needs.

**The Number of Carers = 2,500,000 - The Number of Regions = 44 - Cost per Carer / annum = \$7.20**

This is an insignificant ask when compared to our conservatively estimated \$32 billion annual contribution to the national budget bottom line.

*"In a changing civil society, carers do not have the same rights, nor the same life possibilities as the broader community but they do have the expectation that, as providers of 93% of all disability services nationally, they are entitled to recognition by government, to be supported in their irreplaceable role, to have input to policy and planning and the opportunity to participate in the direction of their own lives."*

We urge all governments and all political leaders to take immediate action to save family caring before it is too late.