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**Submission No. 866**  
(Inq into better support for carers)

Submission to  
Parliamentary Inquiry into Better Support for Carers

submitted by

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## **The role and contribution of carers in society and how this should be recognised**

Carers come in many shapes and sizes, with ages ranging from 10 to 100; as such, there is no way to outline the "role" of a carer, for there are as many variations in roles as there are carers. As it is impossible to describe every variation, the following describe the roles as broadly as possible.

A carer might be caring for a person with

- \$ with a physical disability
- \$ with a psychiatric disability
- \$ with a sensory disability
- \$ with an intellectual disability
- \$ with a brain injury
- \$ suffering from drug and alcohol dependency

The carer might be

- \$ a child or teenager caring for a parent and often for siblings
- \$ an adult caring for a parent
- \$ an adult caring for a sibling, other relative, or a friend
- \$ an adult caring for a spouse
  - \$ where the couple are still young
  - \$ where children are involved
  - \$ or where they are both ageing
- \$ a young parent or an ageing parent caring for
  - \$ a young child born with a disability
  - \$ an adult child born with a disability
  - \$ an adult child who has acquired a disability

When a person has to take on the role of "carer" for a family member, they are placed in an awkward position. They have to learn to balance two roles - that of carer with the role they previously held, as child, as spouse, as parent. They have to cope with the stresses of this role change, not just for themselves, but also for the person for whom they care.

A parent who has become dependent will be feeling the loss of independence, but when they are reliant on their child for care they may

also feel guilt, frustration, shame.

A spouse, whether carer or being cared for, may find the loss of intimacy to be devastating. If children are involved the carer faces the battle of finding time away from "caring" to make time for parenting.

**The contribution of carers to society is immeasurable.**

In social terms, they are the people who keep their family member connected to the world, and to reality. They are the ones who organise and manage daily living, who find, organise and manage services in society, who organise and manage medical care, social interaction, work where possible, daily activities. They are the ones who stop their family member from dropping out, becoming homeless, ending up in gaol, committing suicide. All this applies whether they care for the family member at home or, having placed them in a care facility, have to spend much of their time ensuring that the care provided is adequate and appropriate. Unfortunately, many care facilities do not live up to the standards family want to see provided.<sup>1</sup>

In financial terms, every carer who keeps the family member at home saves society the cost of building and staffing residential units. Consider the cost of round-the-clock care for one person -

- \$ five and a half workers to cover 24 hours, seven days a week including annual leave at a base rate of \$35,000 plus Workcover, Superannuation and any other oncosts that amounts to about \$220,000 in wages alone<sup>2</sup>
- \$ what is the carer's allowance and carer's payment worth?
- \$ what do we pay respite workers?

**How do you recognise the importance of carers? Give them all a gong on Australia Day? What use is that to them?**

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<sup>1</sup> Examples: The resident workers often "forgot" to give a resident his medication; "forgot" to feed him for 19 hours; regularly "forget" to take him to the toilet; if his mother did not organise activities for her son, he would be left to spend all day in front of the television despite the fact that their role is to meet his needs.

<sup>2</sup>The salary quoted - \$35,000 - is below the Average Weekly Income of around \$50,000, so is not exactly generous

If you seriously want to recognise the importance of carers then you need to fund the provision of the services carers need to support the person for whom they are caring - education, therapy, social activities, holidays, respite, care workers

There are several distinct stages of service need for carers and the people for whom they care.

At the onset of the disability, they need

- § specific information about the specific disability - how the disability will affect the person's life, what rehab can be provided, what supports the person will need - this can only be provided by people who have expertise in the field - not doctors, because their training is too general and is directed to "cure" not "care"; this is the role of disability specific agencies
- § disability agencies such as Vision Australia, Yooralla, Brainlink, The Richmond Fellowship learn about a disability by providing services and are then able to provide information - for the agencies, it is a continuous process of learning through doing, and doing through learning<sup>3</sup>
- § At this early stage, and even at later stages, there is great benefit in specialist agencies, for each disability has quite distinctive problems and needs.

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<sup>3</sup>This specialist knowledge is frequently passed on to other agencies either in the form of inservice training, or as trained workers disperse, taking their knowledge with them to new situations

At a later stage, the need might be for more general disability services

§ activity-based to provide social interaction for the person with a disability, but including mixed disabilities

§ activity-based to provide "therapy" without the title<sup>4</sup>

§ providing respite for the carer

And further down the track

§ assistance with networking the mainstream activities that is, one that non-disabled people need and use; for instance, a gym, the scouts, the local footy club

§ information about services available in the local community

§ making contact with these services

§ finding a volunteer within the service or community who will act as a support person<sup>5</sup>

The prevailing concept that it is better to fund the "client" and let them seek out their own services is a copout that simply transfers the responsibility and the work back onto the carer.

§ This may work IF the service needed is a mainstream service

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#### <sup>4</sup>Example

A day activity centre took people with a range of disabilities. "Therapies" were offered informally; Planning lunch, buying the ingredients, making lunch were enjoyable activities that didn't feel like therapy.

Also, each person could use their "abilities" to compensate for someone else's "disability" - the guy with the brain injury could push the guy in the wheelchair

#### <sup>5</sup>Examples

A young lad wants to join scouts, but needs support; he doesn't want Mum to go with him every week; he needs one of the scout troop, with the support of the leader, to pick him up and return him home each week.

A young man loves football, but cannot go out alone; also, he needs to make his own friends independent of mum and dad; the local butcher, a member of the local footy club, befriends him and takes him every Saturday; gradually, he becomes a part of the club, even though he cannot play

- § It does not work if the person needs a disability-specific service - and there is a need for services run by people who understand the specifics of a disability
- § Furthermore, if the service does not exist, who is going to provide it? Is the carer supposed to establish and run the service for the benefit of others?
- § If you leave it to the marketplace to provide services, it doesn't work. The carer may know what is needed, but it probably doesn't exist, nobody wants to offer it because they don't have any clients, and those who need the service couldn't afford to pay for it anyway, so it doesn't make enough money to make it viable.

**The barriers to social and economic participation for carers, with a particular focus on helping carers to find and/or retain employment**

Note: A carer is already employed - they have a job - 24 hours a day, seven days a week, no sick leave, no holiday leave, no long service leave, no retirement fund - no sanity, no life!

Note: there is nothing anyone can do to remove the burden of "caring about" their family member - all you can do is relieve the pressures of money and of service needs

Note: even when you provide all the services a carer may need, the carer still has to organise their use

In order to help a carer stay sane and have a social life, there needs to be

- \$ sufficient care workers to give respite
- \$ a wide range of activities available to occupy the person with a disability, so that the carer may spend time out of the home<sup>6</sup>
- \$ enough money in the Carer's Allowance and Payment to enable them to actually DO something

In order to get a carer out of caring and into the paid workforce, there needs to be

- \$ sufficient care workers to give respite
- \$ a wide range of activities available to occupy the person with a disability, so that the carer may spend time out of the home<sup>7</sup>
- \$ someone (a co-ordinator) to pick up the pieces when the above fail  
Note: Case managers and carer agencies don't seem to be able to do this, though one would think it is their job<sup>8</sup>
- \$ Programs and activities that run all year - at present, most programs for people with disabilities run across school terms and close down for the holidays - why? They don't go to school, their carers don't go to school, and employed carers need them to be cared for
- \$ employers who are prepared to be flexible with regard to hours, medical appointments and emergencies

Note: Carers who work still come home to caring - they are on duty for 12 hours overnight, and this can be as difficult a time as any other - and if a carer has been up all night, how can they go to work the next day and operate effectively? How long before they get the sack?

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<sup>6</sup>Everything from day care centres, to sheltered workshops, to TAFE classes with Special Ed trained teachers, to organised sports activities

<sup>7</sup>See above

<sup>8</sup>What does a carer do when the careworker does not show up? Does the agency supply a replacement? Or does the carer simply stay home from work and fill the gap? What else can they do? And how long before they are sacked for unreliability? And when an activity ceases to meet a need, who spends time finding a new activity? Most likely the carer, not the case manager.

## **The practical measures required to better support carers, including key priorities for action**

- § Increase Carer's Allowances and Payments to a living wage
- § Pay Superannuation for carers on Carers' benefits
- § Pay an allowance to carers who do not live with the person with a disability but still play a role in ensuring the person is cared for
- § Pay working carers an amount to acknowledge their "after hours" caring
- § Provide the additional "living needs" of the person with a disability - e.g., nappies for the incontinent, medication for epilepsy, etc. - so that the carer's money is not going to buy these things, leaving them no better off.

## **Strategies to assist carers to access the same range of opportunities and choices as the wider community, including strategies to increase the capacity for carers to make choices within their caring roles, transition into and out of caring, and effectively plan for the future.**

I do not believe that carers will ever be able to access the same range of opportunities and choices as the wider community, but it is a nice ideal - except for one thing. Most decent people will put the welfare of the person for whom they care before their own welfare.

- § Upgrade the training, status and pay of care workers to professional level
- § Provide a wide range of respite, rehabilitation, activities and alternatives
- § Be flexible in how you interpret your own regulation Make sure that information on carers' benefits are simply expressed, and easily available<sup>9</sup>
- § Make it quick and easy to access the carers' payments when a person needs to drop out of the workforce<sup>10</sup>

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<sup>9</sup>Try accessing the information on the internet, and see if you can interpret it. I am a university graduate in Humanities, have been an English teacher, and I cannot understand the website on benefits.

<sup>10</sup>Complaints about Centrelink procedures and staff attitudes are legendary