



## Submission No. 585

(Inq into better support for carers)

9.a.c. 7/8/08

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Committee Secretary,  
Standing Committee on Family, Community, Housing and Youth  
PO Box 6021  
House of Representatives  
Parliament House  
CANBERRA ACT 2600

Dear Secretary,

We wish to make a submission to the House of Representatives Standing Committee into Better Support for Carers.

We are a group of Carers from the South and East Metropolitan Adelaide and attended a consultation at the Carer Support and Respite Centre on June 23<sup>rd</sup>. The consultation outcomes have been compiled by the Centre on our behalf because they know how difficult it is to find the time and resources to write to you individually.

Our report includes many direct quotes from the meeting so that you can try to understand the situation for Carers and the frustrations that we often feel when trying to access support and services for ourselves and the people for whom we provide care.

Thank you for providing this opportunity for us to participate in the Review. You can make contact with us through the Carer Support and Respite Centre, who have collated all our information for you.

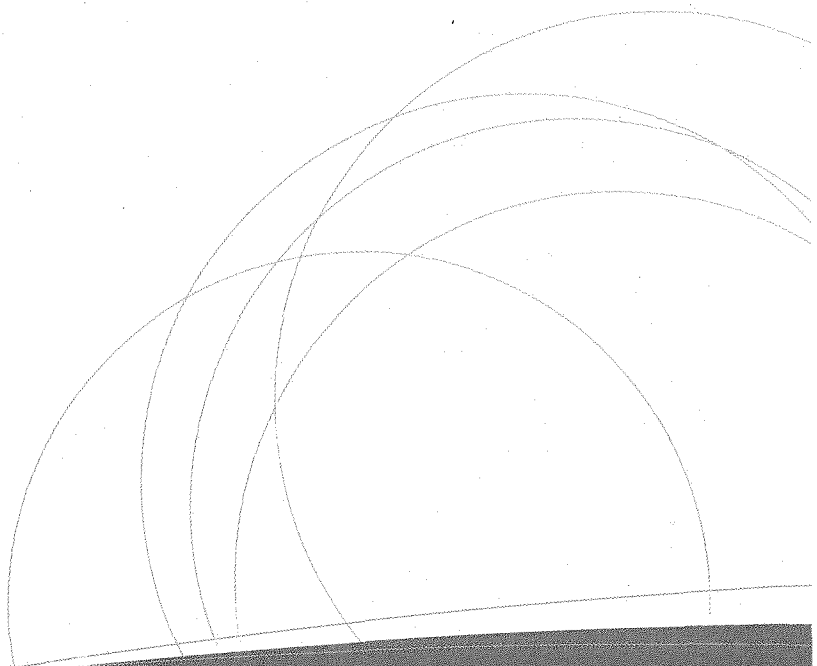
Yours sincerely,

for

Victoria Bridgland, Pam Dolan, Shirley Fckert, Mary James, Vija Jonats, Athina Karabetsos, Peter Lane, Helen Linke, Dianne Stewart, Pauline Walker, Mary Jolly, Kevin Stewart, Debbie Smith, Joffre Toschach.

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## **Some quotes from our consultation:**

*"We are glad that you are doing this Review. I did provide for my future when I was working, but I have now spent all of my superannuation on my son. I have nothing left after paying for modifications to my home, and buying equipment for him. I am now surviving on \$12,000 a year – I would like you to recognise that I help to save the Government billions of dollars a year. In recognition of that I want you to pay me what I deserve and I want you to provide me with something for my future."*

*"I am sick of feeling like I have to grovel every time I need something to help me with my caring role"*

*"We are workers, not retirees. "*

*"The term Carer is warm and fuzzy – it belies the level of knowledge and skills that we have. We are physiotherapists, nurses, teachers and occupational therapists".*

*"This is a human rights issue – where else would you work 100 hours a week, be on permanent 24hour call, have no sick leave, no annual leave, no long service leave."*

*"The intrusiveness of the paperwork is insulting – we have to fill in forms for Centrelink even if our person spends one night in a hospital"*

*"If my son spends one night at a school camp I have to advise Centrelink. Why should I?. Other parents on Centrelink allowances don't have to do this".*

*"Many of us have given up professions and careers. We provided for our retirement through Superannuation, but all that is now gone. We should be paid superannuation from the Commonwealth so there is something there for our future."*

*"\$100 as a Carer's allowance is an insult – incontinence pads alone can cost \$2000 a year."*

*"Carers are the collateral damage of their loved ones catastrophe"*

# Summary of Issues and Recommendations

## Centrelink

There needs to be a massive overhaul of how Centrelink manages Carers, staff attitudes towards Carers and the current eligibility and review criteria.

### Recommendation:

- A dedicated Unit within Centrelink for Carers
- A complete Overhaul of Eligibility and Review requirements with a view to removing the insulting and meanspirited aspects of the current arrangements

## Financial

Carers save the Federal and State Governments billions of dollars per year.

The current system of Carer payments and allowances forces Carers into a life of increasing poverty.

### Recommendation:

- Carers receive a Superannuation payment from the Federal Government at the same rate as is paid to other workers
- Carers are paid the minimum basic wages in recognition that they are multi-skilled professionals in their own rights as Carers
- Australia adopts the "In Control" system which operates in the UK and other countries where control of the expenditure for the Care Recipient is placed with the Carer

## Respite and Support

This is critical for Carers health and well being.

### Recommendation:

- Small cottage-home facilities are purchased/built and staffed so that Carers have access to long term options for their Carer Recipients
- Regular and Planned respite needs to be funded
- Many more High Care community packages are needed
- We need funded support programs for Carers which focus on the health and wellbeing of the Carers – much more is needed than Respite.

## Commonwealth/State

There are considerable overlaps and gaps in services.

### Recommendation:

- That the confusion between roles and responsibilities of Federal and State Governments be resolved so that Carers are no longer caught in the middle with each level of government apportioning blame to the other.
- That the Federal Government pass legislation similar to the Carer's Recognition Act in SA and that a separately created Federal Office for Carers oversee the funding allocated for Carers
- Federal funding arrangements need to be simplified and "needs based" – remove the age barriers and remove the conditions related to the Care Recipient – i.e. funding for Carers to be allocated according to needs of the Carer, and funding for the Carer Recipient needs to be funded according to the needs of the Care Recipient.

## Work place

Carers are productive members of the community and many want to remain engaged with work or else return to work.

### Recommendation:

- That the Federal Government subsidise training for Carers so they can re-enter the workforce or else train for a different job/career.

## **Preamble:**

The Carer Support and Respite Centre held a consultation with Carers on June 23, 2008. The comments and recommendations included in this Submission are entirely those of the Carers. The Centre's role has been only to collate the information on the Carer's behalf. The content has been checked for accuracy by the Carers involved.

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

*Overall there is a chronic failure of Government Departments to recognise the impact on a person's life of caring for their loved one – both State and Federal*

We need to have Federal Legislation to cover the rights of Carers when they interact with Federal Government agencies and federally funded ngo's in the same way as South Australia.

When Federal planning processes are occurring for health, education, welfare, the particular needs of Carers should be included in the planning in the same way that other special needs groups are considered (eg people with disabilities, or people from different cultural backgrounds)

Carers need to be acknowledged as workers. The word "Carer" implies a warm fuzzy role, but we are people with high levels of skills, we are nurses, teachers, physiotherapists, occupational therapists, mental health workers

GP's need an education process to inform them about the health impacts of caring so that they are not inadvertently disadvantaging Carers eg filling the ADSL's and other Centrelink forms

We need a Carer's section with Centrelink – we are not retirees, not unemployed, don't have a disability. We have particular needs which are unique, we are very hard workers who save the government billions and we are sick of the way we are treated when we go into a Centrelink office

How about some TV "advertising" on free-to-air to help raise the profile and understanding of Carers. Similar approaches have been used to impact on public awareness for people with hearing disabilities and also those with mental illness.

We need an advocacy service for Carers – most advocacy services are funded according to the Carer Recipient's needs eg Disability services, Health Commissioner – it is a nightmare to try to get someone to help us negotiate the maze of services and then if we need help to be heard there is no-one there to help us.

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

*We are in crisis when we become aware that the person we love is going to need long term care. It is distressing and emotionally chaotic when it is all happening - we are adjusting to the idea that not only is our family member or friend now dependent on others for support we are aware that our own life is going to change as well. It is a time for major adjustments.*

We need flexible hours of work

The most important barrier to returning to work is the inability to find regular and quality care for the people we care for. Support workers are not paid well, they are not well trained and there is therefore a high turnover in the industry. Our Carer recipients are often unable to tell us if they are not being treated well so we need to be very sure that the care is of a high quality

If we don't trust the support workers then we don't go to work – it is that simple

I will only go to work when my child is attending school – I don't trust the Support workers – many have English as a second language which can make it very difficult to give them instructions which are fairly specific. It also makes communication difficult between the Carer recipient and the Support worker

We need more Respite Houses, but we need them to be more transparent and accountable to Carers and to funders. We feel that we can't make even a small criticism about our child's care because the staff all stick together. Then we worry if our child is going to get worse treatment because the staff don't like us.

How about Respite Houses get Webcams so we can log on at work and see our child. That would help a lot. Police Checks are not enough reassurance that our children will be safe from abuse or unkindness

The Centrelink paperwork becomes a nightmare if we try to work. It is a major disincentive. This is especially the case if we do have a flexible employer – we are filling in forms for every week if our hours vary or the days vary. It is just too hard on top of everything else.

It's easier to stay home and be confident that our child is safe and happy – even if we are absolutely exhausted and need a break or we would love to go back to work so we could earn more money  
How about working from home options with quality in-home respite

Access to retraining so we can return to the workforce. This retraining should be in the form of new training (eg a course of study) or else training to update the person so they can re-enter their career.

Give training credits which relate to the role the Carer has taken at home. Eg for nursing, teaching, mental health work etc

We would love to go back to work but we MUST have:

- Flexible work hours
- An understanding work environment
- Access to high quality support workers or respite houses
- Less punitive action and attitudes from Centrelink

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

*Many of us made sensible decisions about superannuation etc and were providing for our futures. We were not able to foresee the future when we would be forced to leave our jobs, professions and careers*

Carers need a superannuation contribution from the Fed Government. The superannuation we receive when we leave our jobs is used very quickly because of the extra costs associated with the Carer Recipient. We save Federal and State Governments billions of dollars a year – this should come back to us in some form.

Currently we only get 53 days a year respite. It is not enough if we are trying to work. It is not fair that part of our allowance is eroded if our child has a night at a school camp – the costs are still the same for us but we still have to go through all the paperwork to tell Centrelink about ONE night away – it is insulting, insensitive and mean spirited. Also it is discriminatory because people who are on unemployment benefit or disability allowance don't have to advise Centrelink if their child has a night at a school camp.

We struggle with trying to get enough money to support ourselves and the person we care for. The whole system of allowances and reviews must be overhauled as a matter of priority. e.g.

- \$100 as a Carer's allowance but for Rett's syndrome continence pads alone cost \$2000 a year
- \$5.90 a fortnight for pharmaceuticals
- Pressure bandages are not covered but can cost up to \$700 per week
- Families should be assessed properly and financial provision should be made that is adequate – not everyone gets the same. Our situations and needs are different, so we should be funded differently.

The paperwork is so burdensome and intrusive. We are supposed to advise Centrelink if the person we care for goes to hospital for a night.

We need the special section in Centrelink so that our needs can be better understood e.g. some Centrelink officers try to change our allowance from the Carer's payment to the Aged Pension – but this then means a loss of benefit. If we don't know the system really well then we get disadvantaged because the Centrelink staff aren't on top of their game.

We need to sort out the mess between State and Federal agencies. Some examples are:

- We are unable to transfer Support packages across State boundaries
- The Federal Government says it provides respite and support, but it doesn't it provides respite. There is a lot more to supporting a Carer than providing Respite
- The system is really complicated – there are so many overlaps between state and federal agencies. In SA, the support for Carers is funded through HACC which is managed by Office for the Ageing – what about support services for parents of children with disabilities.
- We need a dedicated agency for Carers – stop making access to resources dependent on the age of the Care Recipient, the illness of the Care Recipient, and generally speaking so biased towards older Carers. Carers are Carers. Funding for Carers should be about the needs of Carers – fullstop!
- Recently Novita was given \$450 per family towards a continence aids scheme and the State Government promptly withdrew the State subsidy. This ended up a pointless exercise and was of no benefit to Carers.

## **The practical measures required to better support Carers, including key priorities for action. (cont)**

The Carer's allowance should be at least the standard minimum wage and we should not be disadvantaged if we also try to find work to supplement that.

Training and wage rates for support workers need to be improved. We have all had experiences of support workers not having a clue about what they were doing with our children or partners. e.g. not knowing how to put on a nappy.

Remove the limit on how much "cash" Carers can have. It used to be \$78,000 but has recently been reduced to \$7,000. This is mean. If we have cashed up our Superannuation when we become Carers, \$70,000 will go no-where. Basically it is all gone in a couple of years because of the extra financial burden we are under – e.g. changing houses for access ramps, special equipment, buying equipment which is not funded

We need to change the rules of eligibility for Centrelink – my son's needs didn't change when he turned 16 but his allowance did.

We need a massive overhaul of the eligibility system for Centrelink payments. The current ADSL form for Centrelink is biased towards physical disability – it fails to adequately recognise mental illness.

Can we look at implementing the "In Control" system here which operates in the UK and other countries. This would work much better for us if we could have some control of the funding which is allocated. There are a few isolated examples of Carers who have been successful in getting control of the funds. One Carer said that she was told by the agency that they used to be allocated \$15,000 to provide care for her son. She now gets \$8,000 and is able to arrange more support for her son than when the agency had control.

How about concessions for Carers for a whole host of Government provided services/taxes. What about a Carer's Card with similar benefits as a Senior.

**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 role, transition into and out of caring and effectively plan for the future.**

*We all worry about what will happen to our sons/daughters when we can't look after them any more.*

We need a financial scheme for our children to cover their future costs.

Currently 6,500 young people are in nursing homes – we need to get them into more appropriate accommodation. We will not place our adult sons and daughters into aged care facilities.

De-institutionalisation is an important thing to do for independence but families need a lot of support to cope with this.

We also need high quality residential facilities which are “cottage-homes” not massive institutions

Regular breaks are essential to our health and well being as Carers. We need to be able to ask for Respite without grovelling. There is never enough Respite available. There is no Planned Respite funded by Federal Government and this is essential if we are to cope into the future. It is not enough to only have respite available for emergency, short term and occasional. We need to be able to plan ahead, not just wait for a crisis before we can get a break.