

Committee Secretary  
Inquiry into Better Support for Carers  
House of Representatives Standing Committee on Family,  
Community, Housing and Youth  
PO Box 6021  
Parliament House  
CANBERRA ACT 2600

DEC 17 11 10 AM

Submission No. 865  
(Inq into better support for carers)

Dear Secretary

I wish to make a submission to the House of Representatives Standing Committee on Family, Community, Housing and Youth's Inquiry into Better Support for Carers.

I am submitting to the Inquiry because...

I feel Carers aren't given the opportunity to have a say in these issues and that the general decisions are made by people who do not live this type of life and have no idea how it diminishes our social and economic opportunities. Too much money spent on studies and agencies and not enough getting out to the families doing all the real work.

More information is attached on a separate sheet

## 1. The role and contribution of carers in society

As a carer, I feel that my role is...

To help my son have as normal a life as possible and to enable him to access everyday activities like other teenagers. He is 17 and has Autism and Intellectual disability and lives at home with myself and his step father. I am involved in many carer issues and support groups and share the wisdom and information I glean bit by bit. I am also very active in informing the general public about the realities of being a carer. There is a lot of misguided souls out there. Misinformation too, as most people assume we are well provided for. We don't ALL get paid for caring. My dismal (but welcome) \$100 per fortnight, equates to about 50c/hr over a regular week, not including school holidays etc when it is more like 35c/hr. But we do it for love! The Government relies on us continuing too. My role is severely under funded and unrecognized or supported properly for the amount of time and effort I put in. We are all tired of being treated as slaves MR Rudd. Lucky country? I don't feel lucky.

More information is attached on a separate sheet

## 2. The barriers to social and economic participation for carers

As a carer, I face the following problems ...

We provide care for Ryan around the clock as he is incontinent, has no speech and is unable to do anything for himself. His Autism creates challenges for social opportunities and is very isolating, as we cannot go out much unless we can access carers to watch him. He cannot be left alone as he is unaware of danger as well. He is also medicated for anxiety and I have also recently been diagnosed with stress and anxiety and need support that I don't get. I get some funding for my son but am currently unable to access respite because the centre has run out of high support funding. Ridiculous! Why do I get funding if I cannot spend it and it all goes back to the kitty at the end of every year. Makes the Gov figures look great though! I also feel that my parent role should also have a time limit, which allows for him to go and live in supported accommodation with his peers in the future (next 10yrs) and not his parents for all of his life. That is not normal. I feel the Government does not provide this option for tired parents of children with high support needs. Not everyone can use home care services to

stay at home. It may work for the elderly but not for mental disabilities, with very challenging behaviour. They just aren't accepted in the community. Wrong this may be but it is the truth, and we are living with the disgusting attitudes of others every day of our long long caring lives. He will never been able to live independently and as I have already been caring for 17yrs, I need a life myself like other parents my age. There are no breaks in sight, with huge gaps in funding, respite and permanent accommodation for guys like my son. Retirement isn't an option for us and neither is Superannuation as I have not been able to work often and my husband lost most of his in the nineties. We will have rely on pensions, if they exist, scary thought! Why not put some money into bricks and mortar and allow us the PRIVELEDGE of being able to go to work and earn a living, whilst still enjoying our family and our health. Plus instead of drawing pensions we could actually pay taxes! Our children could still have some sort of life. If you build some village accommodation it would then be able to share costs of doctors/care workers/specialists etc like aged care villages. They would be in a safer environment too, not subjected to insults and evil people who take advantage of the weak. At least think of all the families coming into adulthood and where they are going to need to send their Autistic kids. The younger ones have early intervention so they may be ok, but those with brain injury or Intellectual disability will always need greater support than those with physical/ mild/ mod disability. DHS know how many require this accommodation and yet they still don't get funding. Why Kevin? If you don't want to support us in this crisis then why do you keep funding medical science who are the ones enabling life to go on with extreme difficulties. Both aged and infant's survival rates are much higher now than ever before. Lets cut out saving premies and play god. Lets deny oxygen to those victims of motor accidents/stroke/cancer etc. Lets play GOD! HMMM you do when it comes to carers. Ok for one group of society but seems very inhumane! We are not in minority any more and we will not continue our free care forever! Trust me!

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*More information is attached on a separate sheet*

### **3. The practical measures required to better support carers**

As a carer, I need help with ...

Support for me and my family by way of financial, respite, time off, ability to work, have a holiday, spend time with friends etc. Like everyone else I want a life. I didn't choose to become a Carer. It wasn't a chosen profession. I did it because that is what you do when you bring a newborn home from hospital. Just that 17yrs later nobody has stepped forward to relieve me of my role. You need to seriously look at the way Carer Payment is set up. It should not be the same rules for those caring for elderly or sick parents as for caring for children with disabilities. They are only caring for a short time mostly and have had jobs/lives/holidays etc. Our role is on going with no future ending. We have no opportunity to amass assets/ savings/superannuation etc, but we are penalized for trying to earn more money. I cannot even get a payment because I have a working spouse! He earns more than \$250 p/f. Who doesn't??? Every dollar over that ridiculous figure is taken away from the payment, so we would lose it all if we bothered to apply. But we both need to work as we were fortunate enough to buy a house. Modest, 11squares, but still have a mortgage to pay like everyone else. Both parents need to work these days. My wages cannot be replaced unless I get some regular, affordable, reliable care for my son. We are of the generation who missed out on everything, baby bonuses, first home buyers grants, school support, early intervention, etc. We are still missing out. How about a one off payment for those of us caring

who haven't been able to access Autism support, but have kids over the age of 12. Our kids need speech training too. They need much much more than we can ever afford on one wage. It's criminal the way the Gov keep throwing money at sports that cost millions and don't give back to those of us who are saving them billions! The one off bonuses do very little by the way. Our \$600 went on my husbands rego, as we don't have a health care card. We pay full rates for everything. My son gets a pension and has a health card but its not his house so it doesn't help the family budget. All carers on the allowance should get a health care card too, especially when we are forced into lifelong care. I am on medication for my own stress due to caring and I have to fork out over \$40 a month for them.

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*More information is attached on a separate sheet*

#### **4. Strategies to assist carers to access opportunities and choices**

I think the Government can better help carers by ...

1. Improve services and support by providing more information to families about our rights to funding and programs. Very poor communication which doesn't show real need/gaps in services, because nobody knows what is available because its secret and underfunded.

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2. Increase carer payments to meet realistic cost of living and change the qualifying rules for each different caring situation.(some get TAC money and draw a pension whilst others don't even know about it)

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3. Make service providers accountable for spending of funding earmarked for families. We are not getting it, it's going on admin costs, office equipment and wages of people not doing their jobs. Don't include funding for admin in figures provided to the media. Its not accurate for what is actually spent in assistance to families.

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4. Build some accommodation villages like aged care, for adults with disabilities to go to after their familias are burnt out. They need high supported programs and good staffing. We need peace of mind that they are safe and have somewhere to live when we die.

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*More information is attached on a separate sheet*

Thank you for taking my views into consideration as part of the Committee's Inquiry. I look forward to reviewing any recommendations you make to improve life for carers in Australia.

Yours sincerely

*(Apologies if too late in- life got busy but I want to be heard)*

*Signature*

*Karen and Gary*

*Print your name*

*4/7/08*

*Date*

*Postal Address*

*Contact Telephone Number*