

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

3 July 2008

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.

My name is Donnelle and I am the primary Carer for my daughter Samantha, who is 14 years of age. I am married to Conrad and have two other daughters aged 11 and 8.

As a Carer, I feel that my role is seriously undervalued. There is not enough recognition to the contribution Carers make to society and a lot more support should be provided. In the past few years in Kalgoorlie at least, Carers' Week has passed by without notice, or if an event is held it is to recognise aged-Carers and not the many other Carers who exist. We really are a hidden part of society. However, to me it's not public recognition that is important, it's the recognition of Government and other agencies that means much more.

I feel the government must also do more to recognise the contribution Carers make and the cost of caring. Our daughter was born with severe and multiple disabilities and now at 14 still requires the same amount of care as a baby – we need to feed her, dress her, bathe her, change her nappy, brush her teeth, do her hair, get her in and out of her wheelchair or wherever she is "sitting", put her splints on her feet, ensure we have the right equipment as she grows, talk and meet with physiotherapists, occupational therapists, speech therapists, disability services, school – the list goes on. Due to this extra care I am unable to participate in paid work full-time, for if I did I would be constantly taking time off for appointments. This cost of caring is difficult to put a figure on but I feel it is certainly worth more than the \$100.60 I currently receive for Carers' Allowance each fortnight.

In addition, living in Kalgoorlie where there are better work opportunities for my husband means that we have no family support network to rely on. We are heavily dependent on local agencies to help us with respite and caring for our daughter. So much so that some of my best friends are the support workers or care aides who come to assist us. Furthermore, because we live in Kalgoorlie but often have appointments in Perth, we need to juggle the entire family and either all make the trip or my

husband must take time off to care for our other children while I travel with Samantha.

Our daughter's needs affect almost every aspect of our daily lives, constantly. Our daughter's needs affect the style of house that we live in, the car that we drive, holidays we may take (which are few and far between), any plans for the future we may make, and any financial planning we might undertake. Her needs also affect the activities we do with our other children and impacts on their lives in many ways as well.

These days we need help with the day-to-day care of our daughter. As Samantha gets bigger it is becoming more difficult to carry out simple tasks single-handed. Silver Chain Nursing Association now assist us with showering Samantha four nights per week, but when I requested a fifth night I was charged \$38.10 per hour. I paid this for a little while but it soon ate into the respite funding that I had and I cancelled it, preferring to use the funding for more rewarding respite. It seems that many care packages are targeted at the elderly and that children are often not included as those that need assistance.

The cost of nappies is another area of concern. Whilst Samantha is on the Continence Aids Assistance Scheme, the funding of \$479.40 only pays for 18 packets of nappies, which lasts about 3 months. For the remainder of the year we must buy them ourselves. Due to Samantha's age and size we must purchase specific nappies and not the type readily available in supermarkets. Each packet costs \$25.75, so for the remainder of the year nappies cost us approximately \$1,390, add to that the cost of wipes and gloves at about \$20 per month at least, and the CAAS funding seems insignificant.

While I am acutely aware that money does not solve all the problems, a fairer system would go a long way towards helping. Imagine how Carers felt when the new Government did not commit to the bonus payments earlier this year! We need that extra money to cover the extra costs that we face every day - we do not need uncertainty. If nothing else, I would like to see the Government legislate to make the bonus payments an annual event without any uncertainty.

Another way in which the Government can better help Carers in by ensuring there are enough short-term respite places available and that many more full-time supported accommodation places become available in the future. There will come a time in the future when our other children leave home and my husband and I are ready to retire. I would like to think that we can plan for that knowing that Samantha will have also moved out into a suitable home with her peers, and that we will be able to do the things that most people take for granted at that age, and perhaps make up for the time previously spent caring for our daughter.

Please believe me when I say that we love our daughter dearly, as we do our other girls, but it is not an easy role being a Carer instead of just being a mother or father or sister. There are days when I just don't want to get out of bed because I know when I do it will be the same old routine of getting Samantha up, changed, dressed, fed and ready for the day, and it will always be this way. She won't grow out of it or learn to do any of these things for herself. It will always be the same.

So please, increase the CAAS funding, legislate for the Carers bonus payments and increase funding for supported accommodation places. And if you are in any doubt as to how difficult it is to be a Carer, spend some time with a family that is living it every day.

I feel that I have in no way included all of the issues that have confronted me as a Carer, or our family, over the past 14 years, or even come close to explaining the frustration that we sometimes feel in our caring role. However, I would like to 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,

Donnelle