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Submission No. 1025

(Inq into better support for carers)

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

Dear Secretary

I wish to make a submission to the House of Representative Standing Committee on Family, Community, Housing and Youth's inquiry into Better Support for Carers. I am 47 years old, married with three children. My middle child Jenna, is nearly 14 years old and has a chromosome abnormality. She has a severe intellectual disability, is profoundly deaf, has turned feet and low muscle tone. She can crawl but not walk independently and uses a wheelchair for mobility most of the time. Jenna is incontinent and needs as much care as a nine month old baby.

I feel my role as Jenna's primary carer is a big, important job which is very time consuming and hard work. I feel I contribute to Australian society by providing this round the clock care for which I only receive the Carer Allowance of \$100.60 per fortnight.

My family is struggling financially because I cannot work full days, I can only work within school hours as there is no Out of School Hours Care for high school age children with disabilities. I have applied for a flexible respite package but was not offered any respite. Therefore, I cannot apply for jobs that are full days. I do have some family living on the Central Coast about 30 minutes drive away, but they either work full time or are too old and physically unable to manage caring for Jenna. If I give up the average 10 hours a week work I am doing now, we may be able to receive some Carer Payment. However, we would be worse off financially than we are now, as it would not give us much help as my husband works full time. I feel all carers should be recognised financially for the huge job we do which disadvantages us financially. We have a home loan we hope to be able to pay off before we are 65 years old, but not being able to work full days to earn more money keeps us struggling. We would like to be self funded retirees one day, but I feel this is beyond our reach due to our financial circumstances. I worry about our future, how can we get ahead?

I can't fully participate in social life because there is very little respite available to care for Jenna so my husband and I might go out. We can only go out if we are lucky enough to receive overnight or weekend respite which is not very often. Where can we find casual care that doesn't have to be specially requested from DADHC 4 to 5 months in advance.

I have had a lot of trouble trying to find out information about services available to my family and child through DADHC as there is a very long waiting list to see a Case Worker. There are not enough Case Workers. Case Workers seem to be allocated on an in crisis basis only, otherwise you just keep staying on the waiting list. It is not much help.

I have been told that in my area of the Central Coast, New South Wales, that the waiting list for a place in a group home is very long with about 160 other disabled people waiting for a place to live. Even adults with disabilities should be able to leave home one day, allowing their parents to retire. We need more group homes in our area.

In July 2007 the Continence Aids Assistance Scheme (CAAS) was opened up to children with disabilities too. At the same time the quantity of continence aids (nappies) available to children with disabilities through PADP (a part of Area Health) was reduced from 80 nappies a month (12 cartons a year) to a total of 8 cartons per year. The CAAS money allowed us to buy 4 full cartons and 3 packets each 20 nappies. So the change in service delivery only gave us 60 extra nappies a year. We all believed we were being offered real help not just a token effort. We spend on average an extra \$1000.00 per year on the additional nappies and pads we need for Jenna. Please remember all this will go on for years and years, another financial burden.

Families of children with disabilities are being discriminated against. In New South Wales, children with disabilities do not have a right to the same transport subsidy scheme able bodied children do.

In the 2008 Federal Budget it was announced that from 1st July 2009 an expanded eligibility criteria will be introduced for families applying for the Carer Payment Child. Apparently eligibility will be determined on the amount of care required, rather than a list of specific medical criteria, however, eligibility has always also been based on the families income. Will this unfair income test be removed or at least reviewed to take into account the fact that we are financially disadvantaged because our daughter was born with disabilities and we have many extra costs to cope with due to her disabilities?

Our quality of life now and in the future is lower than families who do not have a child with disabilities, due to a lack of flexible respite, out of school hours care, financial support and supported accommodation for adults with disabilities. As we age I worry that our health will deteriorate and we will still be looking after Jenna full time.

We love our daughter but in many ways our lives are on hold being full time carers of a person with high support needs.

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

Yours faithfully

Linda