2/72008

Part rec 17/7/08

Submission No. 868
(Inq into better support for carers)

Committee Secretary
Inquiry into Better Support for Carers
House of Representatives Standing Committee on Family
Community, Housing and Youth

Dear Sir /Madam,

I am writing to you as a carer living in Bathurst NSW.

My son was born with multiple disabilities 13 ½ years ago here in Bathurst.

I also care for my elderly parents and my 90 year old mother-in-law who lives near Orange 45 minutes away from Bathurst. My Father has been unwell for a long time. He and my Mother live next door to our family, however my Father is currently in hospital in Sydney .Needless to say it is very difficult to even visit my Father whilst he is hospital due to lack of respite.

Since my son was born in 1994, I have not been able to access adequate respite.

As a carer I have contributed to this community by ensuring my son has not ended up in an institution or adopted and yet there is very little recognition in terms of financial support and infrastructure for my son's future which reflects the lack of recognition of my role in Australian society.

I have had to use the local hospital to have a break from caring for him. His needs are high and ongoing. He is tube fed wears nappies and had two major operations on his legs to help his mobility. He cannot speak to communicate and needs to be watched so that he remains safe.

For 11 ½ years I have actively searched for child care for him in Bathurst but constantly faced discrimination because of his high needs. Services here put children like mine on waiting lists for a very long time.

The monitoring of child care services to see if discrimination is occurring is not apparent.

There isn't adequate funding in child care services for disabled babies.

Regulate the child care industry to stop hidden discrimination. Carers are being treated unfairly because their child is too different to be cared for and whilst services may not openly admit this is true, it is happening.

There is ignorance in this community which perpetuates the lack of inclusion to children like mine.

Two years ago, I was finally able to access regular respite with him and access some employment.

To access overnight care for my son I have to travel hundreds of kilometers to Sydney. It is very expensive as I have to stay near the Respite Centre as part of the condition that he accesses that service.

As an unemployed carer for so many years I have not been able to build up any significant superannuation which means there will be a greater chance that I will be dependant on the government for a long term pension.

Overhaul of superannuation benefits for carers is an urgent priority if the government wants to address practical measures to better support carers.

My son will need to access locally a supported accommodation facility as he gets older as he will need care for all his life. There are no supported accommodation options here in Bathurst.

At the end of the day I am like any other parent who wants to do a good job raising their child and then have something to look forward to as I age.

Peace of mind.

Is it any wonder that many carers also have a mental illness through their treatment and disregard from the Australian community?

My son's incontinence is another huge problem because I am spending hundreds of dollars on his nappies every year. Even though there is some assistance through PADP and CAAS it is simply nowhere near enough.

The local PAPD service, which includes the wheelchair clinic, is being relocated to Sydney without consultation to the local community. Carers here are panicking as to how they are going to be able to receive the assistance they need without travelling hundreds of kilometers to have a screw adjusted on their disabled person's wheelchair.

The government is bringing in an extra tax for people buying expensive cars, but for some carers they need an expensive car to put their child into because their child's body is different from other normal children and or they need room for a wheelchair. Have any provisions been made to exclude carers from this tax?

Why should carers be penalized through imposing extra tax for purchasing an expensive car to transport their child? Carers of people with such need should be significantly assisted to buy an appropriate vehicle so that they can access the community like other Australian citizens.

Another major obstacle in looking after my son has been the income limits that have been placed on our family since he was born. It's as though it costs nothing to have a severely disabled child so there are all these income limits placed on a family to ensure that they remain always struggling financially. Is it any wonder why there is such a high rate of marriage breakups amongst families with disabled children?

My partner has always worked but we are a family of four who have lived mostly on one teacher's wage. As my partner has worked I was not eligible to apply for a carer's pension to care for my son whose needs equate to a full time job.

Instead I was able to access the carers allowance of about $50.00 per week.

I have just spent over $300.00 in the last six weeks on nappies that could not be provided by PADP or CAAS. Loss of income through the inability to work because of inadequate services has been perhaps the greatest hindrance of having a child with a disability.

I would suggest that every maternity unit in Australia warn parents of a disabled baby, that if they choose to take their baby home with them, they will receive minimal help from the government and probably destroy the quality of life they had once known.

Counselors should be able to speak to every mother of a disabled baby before she leaves the maternity ward.

The government should come clean and admit they will not assist those genuinely in need.

I am unable to pursue my personal interests as I am always caring for my son. Every night he is tube fed, managed and cleaned and put to bed. I don't think it is appropriate for me to be doing all these things for him at his age, but there is little sign of this ending in the near future, unless I leave him at Respite one day and walk away.

My partner and I rarely can go out together on a night out in a spontaneous way as other couples do because there is no service to provide that type of care for our son.

My role to the community I feel is greatly undervalued. I have saved the government a lot of money; say perhaps, at least one million dollars by not walking away from my caring role. Yet I have only ever received a pittance of a carer's allowance since my son was born.
This situation needs to be reviewed, urgently.

A carer looking after a child or adult person with high needs should be eligible for a carers pension even if the partner works as the cost of caring for someone else has life time of hidden expenses.

The income limit should be raised to at least **$150,000** before a family is penalized.

Even though my son has multiple disabilities and has been tube fed for close to 13 years and he has a Health Care Card, I as his carer receive no card to acknowledge that I have sacrificed a career to ensure his well being. We as a family have mostly existed on one teacher's wage. This is how the Australian community has shown disregard for my role.

Currently we as carers are expected to accept that we should not be eligible for income assistance and that we shouldn't need help if we have an ordinary wage.Centrelink's policy makers for the assessment of the cost of living for carers and the income limits they set needs to be investigated by the Ombudsman and the results open for public debate.

Every major town in rural Australia needs a Respite House for carers.

Supported accommodation in Australia is in desperate need. The policy makers at the federal and state level of government needs to consult the community before advising the treasury's office as to how much of taxpayers money needs to be directed to supported accommodation and the results open for public debate.

I find it difficult to believe that these issues are not already on the table to be discussed and wonder which government is ever going to fulfill its responsibilities to Australian carers.

Finally I would suggest that the government look at spending the surplus on infrastructure for people with disabilities and set to make an example to the rest of the world on how the Australian government really does give all Australians a fair go.

Louise
Mother and carer