



AOC 4/8/08

Submission No. 1142

(Inq into better support for carers)

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

Dear Sir/Madam,

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 have been caring for my daughter with an intellectual disability for over 24 years now. I feel that my **role as a carer** is important. My daughter has been able to stay at home, we have got to know her special needs and challenges when she was growing up. We have been there during challenging times when she has had depression and have been able to give her 24 hour care over many months. She has grown up to be a happy young lady contributing to society in many ways. Caring for her at home all these years has given her individualised care has saved the government a lot of money.

I contribute to Australian Society by making people more aware of a person with disability, their challenges, needs and dreams. I have been not only my daughter's carer but also advocate for all these years. During her school years I spent endless hours at schools with teachers, medical professionals, therapists etc trying to make them understand my daughter's needs and how to help her best. I have contributed to society by caring for my daughter at home, our family, friends and neighbours have seen during the years what challenges our family life has faced and how we have still kept going.

I face the following **problems/challenges** at the moment:

- I have to work in the evening, weekends and overnight because I need to look after my daughter during the day, this means the family can not be together very often
- I have not been able to have a fulltime job since my daughter was born, she is 24 now
- I have not been able to find any kind of work for my daughter; there are long waiting lists for employment agencies that provide support for people with disabilities
- There is not enough work opportunities for people with disabilities
- We have minimal funding for my daughter for activities in the community. We have only three hours of funded care.
- It is very difficult to find meaningful activities for my daughter on a daily basis unless I am doing it myself
- I feel I have done enough in 24 years, I would like to have some time for myself too

Our family has been **socially isolated** because of my daughter's disability. Family outings, holidays and get togethers at home have often been a challenge. We always have to consider possible challenges that might come up because of my daughter's disability. Other people do not always have understanding and patience in situations where things do not go according to plan. Going to new places has been stressful as it is not possible to

plan ahead exactly what could go wrong. Therefore we have often given up on participating in activities, celebrations etc because it has been too hard to face the possible challenges. I feel the relationship with my husband has suffered as we have not been able to spend much time together in the last 24 years. We have been away together only three nights since our daughter was born. After every holiday we decided that next time we will organize respite for our daughter and have a holiday without her but it always seemed to be more difficult to organize respite than taking her along. And then the holidays always happened on our daughter's terms and not so that we could have all done activities that we would have enjoyed.

Financial struggles are huge when you have a child with disability. I have not been able to have a full time job since my daughter was born. There has been lots of extra medical, therapy, assessment, medication, etc bills to pay during the last 24 years. Also the cost for respite care is expensive. Respite care gives us some time off occasionally. Support for my daughter needs to be ongoing; she will never be able to live on her own. We are hoping to get extra funding soon so that we can plan ahead.

I would be able to have full time work if there would be enough support for my daughter. She needs to have supported employment or funding for support to do volunteer work or other meaningful activities during the week outside the home. At the moment she only has 3 hours of supported activities during the week, we pay for some other activities but the rest of the time I or my husband have to be at home. Another problem is that supported activities are for short periods only usually three hours with gaps between activities and transport to and from required. There is no program long enough that would allow me to work a full day.

Priorities for action:

More funding for people with disabilities. This is necessary to prevent parents' burnout. It is much cheaper for society to have children with disabilities stay at home than in institutions. But this should not be at the expense of parents' life, they should not have to dedicate their whole life to their son/daughter with a disability.

There are various employment agencies in Canberra for people with disabilities. However the amount of available jobs for people with disabilities is minimal. Business and public service need to be more open to accept people with disabilities into the workforce. Many people with disabilities have lots of skills; they are very hardworking and loyal if they can find a suitable job. People's skills and interests need to be taken into consideration so that employment opportunities can be successful.

Better planning for future, carers need to know that the person they are caring for will be looked after. As carers are getting older the stress level rises if there is no plan for the future. Eventually they cannot continue caring any more and there needs to be a transition and long term care plan in place for the person they are caring for. This means much

more supported accommodation, not just group homes but accommodation where a normal person can assist in exchange for subsidised rent or a lot of support for a disabled person in their own flat. My husband and I are now of an age where after another ten years our ability to continue as carers will become problematic and the government or a charity will have to take over and there are many families much closer to not being able to continue the caring role. This will become a very embarrassing and difficult situation for government unless much more is done very soon.

Strategies to assist carers to access the same range of opportunities as wider community.

When children with disabilities go to a special school it is often difficult to find after school care so that parents could have normal working hours. After they finish school it becomes really impossible to organize care for their sons/daughters as the services are not there to support older people with disabilities. Parents have ongoing stress having to reapply funding every year to keep working or keep caring in general. There is always uncertainty of programs being continued, funding being recurrent etc so parents with children who have a disability are always living on edge waiting for something unexpected to happen in these areas.

If we could have a system in place to avoid all the above, parents could have opportunities as wider community.

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

Marja,