

Submission No. 160
(Inq into better support for carers)

A.C.C. 26/6/08

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

12TH June 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.

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

... is to ensure that our son's needs are met and that he has quality of life. He is unable to speak for himself or to meet any of his needs independently so he needs someone who loves him and looks out for his best interests to advocate on his behalf.

I want to be free to be his mum, not his therapist, secretary, equipment consultant etc.

Sadly, due to the extreme nature of our son's disabilities and the worsening of his physical condition as he grows older, I must let go of some of the ways I'd like to mother him: I have to give up always being the one to tuck him into bed, I have to accept that kissing his cheek will usually upset him etc. However, potentially, I can embrace all the other ways that I can be his mother: by giving him a tickle in just the way mum does it, by showing him his favourite black and white book featuring hand drawn faces, by telling him how much I love him and so on. The trouble is that when you are the primary carer for a person with such high support needs it can be very hard to even focus your eyes, or to stop and savour the moment as you are so busy addressing the many, and ever changing, physical and emotional care needs of your child.

I face the following problems ...

Finding and keeping quality, reliable persons (support workers, therapists etc.) to assist me in meeting our son's physical and some of his recreational needs as well whether this in in our own home, or in a

respite setting. This makes it very difficult to regularly practise self care designed to enable me to keep caring. Support workers need to be paid more, to have more incentives to remain within a particular organisation and highly skilled support workers need to be paid even more. They need to be regularly provided with paid time to enrich their personal capacities to continue caring (exercise/massage/counseling/team building/receive regular one on one delivery of positive feedback received from clients and their families and other recognition of their value to individuals and the community. With quality, dedicated, supported support staff I would actually receive the intended benefit of this assistance.

On-going, in fact worsening, family financial pressures. We could very much be assisted by receiving financial help to

a. purchase specialist equipment etc. our son needs (e.g. wheelchair van: he could not go out in the family vehicle ever if he we did not own one of these),

b. to purpose build an extension to our home so that our son could remain in the family home for a number of years more, and

c. to partly meet the additional medical/psychological costs of private psychiatric/clinical psychology services as there are insufficient government funded services like this available to us. Each one of our other children plus my husband and myself have needed professional clinical psychology/play therapy services at various times since our son with disabilities was born.

The financial burden is a heavy, daily one and causes a great deal of friction in our household, seriously threatening our marriage. Due to the impact of years of frequent night waking, frequent medical appts for our son, hospitalization etc. both my husband and my earning capacities has been severely restricted. Significant on-going funding which meets the needs of people with disability would reduce considerably the financial stress carers face. The suggestion of a very small tax (like the Medicare tax) would go a long way to funding equipment, home modifications, related family medical costs etc. at a level of NEED.

Also additional payments to carers whose caring duties significantly restrict their ability to do paid work.

But even with ideal support, it may have been that my husband and I would still have made the heart wrenching decision to seek out of home accommodation support for our TWELVE YEAR OLD son given the complications and ever increasing complexity and demands of his care. But we'll never know because we only know what was. Tragically, despite receiving funding from our state govt. for this purpose there is no suitable place available for our son to live so he is in emergency accommodation (an adult hostel with 15 other residents.) and where he is very unhappy. To add to our legitimate concerns for our son's well being, the hostel staff view our efforts to know about our son's daily life as intrusive and they fail to acknowledge the trauma associated with this transition for each member of our family. It is difficult for the service provider to overcome staff resentment towards caring for a child in an adult care facility when the staff already feel they

have low job status and are overworked and underpaid. So again improvements to the status and income of paid carers would make the family carer's role less demanding.

Before this time, and now, I find that to ensure our son's needs are met, I must spend valuable energy being 'the squeaky wheel' to keep asking that my son's urgently needed orthotics are funded EACH time he outgrows them, or to train myself vacation care staff allocated to support our son, or to convince senior managers that my son did need outings even if this arrangement was 'emergency.'

d. finding a balance between meeting my son's needs and our other children's needs

e. finding time and energy for my relationship with my husband

I need help with ...

1. Rediscovering my own identity and support to regain mental and physical wellness again. I could well do with some life-coaching, personal training, help to join and play in a sports team: a mentor looking out for me. I lost that when my mother died and our son was two years of age.

2. the availability of suitable accommodation CHOICES less than thirty minutes from our home so that our son has a safe, homely place to live and so that we can easily see him and continue to be a loving family in his life; By the time our son was two, probably much earlier, health care professionals would have been able to accurately predict his need for high level support, therapy, equipment etc in his lifetime. I understand that the needs have been predicted, but the funding dollars and creative solutions have been lacking. Families don't need ANOTHER crisis. The disastrous circumstances of our son's emergency placement mean it will take much longer for him and us to transition successfully and it will be much longer before I am able to work more hours. This process should have been carefully planned and taken step by step...but we might have waited two years before suitable, or reasonably suitable, accommodation options became available for our son. We couldn't keep going one more day...

3. recognition that my caring role does not stop when our son moves into accommodation support: I still attend his various appointments, buy and choose his clothes, have him home with his family at regular intervals, advocate for his needs and those of others affected by disability e.g. the needs of his young carers (his siblings)

4. Acknowledging the huge impact that caring for a person with severe/profound disabilities, from birth, whilst trying to raise a family has on the entire family. The family is trying to grieve for the child they thought they were going to have whilst they are trying to look after a baby and often other young children. (In our case we were also grieving for a co-twin who was stillborn at 34 wks and conceived 'naturally.') The family income usually drops dramatically

as one parent is forced to give up work. Extended family and friendship networks often drop just as suddenly as extended family and friends can't cope with the reality that this family now faces. Mothers and fathers, equally, need LOTS of support at the time of diagnosis and in those first years. In another way, they need lots of support as the years go on and they haven't realised how much time and energy goes to this. There is a value in individualized support and also in small group supports, but especially in support given from 'ordinary' members of the community. Specialised training for people of all ages from all walks of life, including retirees, to 'walk alongside a little' families like oursa bit like the Little Brother/sister program with youth mentors for children perhaps.

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

1. Extending carer payment and the other carer benefit to carers who exceed the designated days away from home allowed in the cases of people with severe/profound disabilities. People like my son require such high levels of support from a variety of sources that it's ridiculous to compare the additional time and effort I provide to meeting my daughter's significant additional needs (three x different therapies, med appts, extra time meeting with educators_etc.) to the HUGE additional needs of my son with profound and multiple disabilities. The inequity is enormous. I feel that my contributions to my son's care are underrepresented by the government.
2. Initiating sustainable funding solutions that will enable the present and future needs of people with disabilities to be met in an equitable and timely manner e.g. further tax incentives to corporate financial support, the medicare type 'disability' levy suggested earlier
- 3,. By not allowing carers to do unpaid work in their family homes that contravenes oh\$s regulations and instead provide them with appropriate working conditions (space/equipment) that shows respect for their significant contribution to society in caring for their family member.

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
Julie