

Submission No. 773
(Inq into better support for carers)

AOC 15/7/08

29th June 2008

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

To Whom It May Concern:

Thank you for the opportunity to make the following submission to the Standing Committee on Family, Community, Housing and Youth regarding the Inquiry Into Better Support For Carers.

Personal Background of the Undersigned:

Leane Leggo:

I have been the primary carer of my son, Mitchell, aged 9, since his birth. Mitchell has severe disabilities and health problems relating to his prematurity including left hemiplegia (a form of cerebral palsy), epilepsy, hydrocephalus, autistic tendencies and behavioural problems. He started walking at the age of 7 but is still reliant on his wheelchair for long distances and for behavioural control. He is also incontinent and non-verbal and uses two electronic communication devices and facilitated communication.

My husband, Geoff, is employed full-time and we have a daughter, Sarah, aged 11. I have endeavoured to remain in paid employment part time with limited success in the past (5 positions over 9 years). At present I am employed 30 hrs per week and finally believe that this situation will continue on a permanent basis.

1. The role and contribution of carers in society and how this should be recognised;

Carers provide an undoubtedly vital role in the care of others with ongoing needs due to a long-term medical condition, a mental illness, a disability or frailty. The cost saving benefit to the Government and taxpayers is billions of dollars every year. Carers are often required to take on many roles: nurse, therapist, teacher, personal care attendant, psychologist, medical researcher, advocate and lobbyist – and now parliamentary submission writers!

At present, government agencies and some professionals in the disability industry do not respect a carer's right to make choices regarding the person they are caring for. Funding is fragmented, coming from both State and Federal budgets with no clear traceability. Small amounts are distributed over many areas such as respite, aids and equipment, home and community care packages, incontinence funding, case management, integration aide, school assistance and others.

Recommendations:

- a. Carers need to be recognised as thinking, able adults. Every caring situation is different with differing requirements. A carer of a child with profound cerebral palsy may require a significant amount of in-home assistance, another carer may require their autistic child to be stimulated more outside the home or require greater assistance in the classroom. Some caring situations require a great deal of equipment, others require higher supervision.

There is often very little control or choice in caring situations so choice in how the funding is spent is critical.

2. *the barriers to social and economic participation for carers, with a particular focus on helping carers to find and/or retain employment;*

Many carers are isolated due to their caring role with little time or energy left over for themselves, let alone a job! *Please do not make these carers go out and get jobs too!* Provide them with respite from their responsibilities rather than adding to them.

For the rest of us, paid employment gives a much needed boost to self-esteem and provides not only some small economic independence but a chance to be ourselves outside the caring role. Unfortunately, from my own personal experience, finding and retaining employment is not easy.

Gaining employment – I have excellent office skills and have not had any trouble getting a job interview. However, the positions I have had to apply for have been well below my skills and ability as a P.A. At an interview you are often asked what attracted you to the position with the requisite answer being “I have a great interest in this industry”, or “I believe the job will enhance my skills and experience”. A more accurate answer in my position would be “I can do this job and it fits in with my caring role.”

I believe you should be upfront about your caring responsibilities, however this often means you are automatically not considered for many positions, regardless of how well suited.

If you have been honest about the flexibility you require and are still employed in the role, you may, rightly, believe that your employer understands and is sympathetic to your situation. Once employed, however, every request for time off for appointments or requests for flexibility in working hours to suit your partner's or respite or childcare arrangements is often met with exasperation and reluctance to accommodate. I have had to resign from two positions due to this inflexibility and have been asked not to return to work on one occasion after my son required emergency surgery and I had to stay with him in hospital for two weeks.

My current position as a co-ordinator/PA allows me flexibility in my working hours, time off for appointments and ability to work from home some days during school holidays. In return, my employer receives a highly skilled, dedicated employee who is willing to work evenings or weekends if required and take on additional duties willingly and without extra pay.

Recommendations:

- a. Provide additional funding for childcare places and for SNSS funding.
- b. Help to foster a change toward flexible and family oriented employment by providing this flexibility in the Government's own employment practices.
- c. Increase pension payments to those carers unable to work to truly reflect their value and financial needs.

3. *the practical measures required to better support carers, including key priorities for action; and*

It is impossible to separate the needs of the carer from the needs of those being cared for. Over the first 5 years of Mitchell's life, the biggest requirement for our family was therapy for Mitchell, to give him the best possible outcome in later life. Funding for early intervention is woefully inadequate. Mitchell received 2 hours a week for 4 years – spread between physiotherapy, occupational therapy, speech therapy, group and social interaction learning and essential life skills. During this time, Mitchell had to be taught every little skill which most of us take for granted: looking at people when they talk to you, responding with a smile, drinking through a straw, eating with a spoon – not to mention the big stuff like walking and talking!

Give carers a choice. When Mitchell was a baby, he required my attention – not another carer. I requested assistance from the local council with cleaning the house rather than respite. I was told, in no uncertain terms, that unless I was physically incapable of cleaning the house myself then I would not get any assistance. However, I could still have someone "babysit" my son while I cleaned the house!

Include specialist therapy services in the list of funding. Speech, OT, physio all cost above \$70 per hour to provide with private health insurance only contributing to a fraction of this cost. Medicare will now fund some limited services, however gap payments are still required.

Recommendations:

- a. Increased early intervention funding to include time without the parent or carer present – this can incorporate the need for extra therapy and life lessons with respite opportunities for the carer.
- b. Provide choice of services to cater for the needs of the carer and their family – not just one-size-fits-all bureaucratic rules.
- c. Inclusion of specialist therapy services in funding.

4. strategies to assist carers to access the same range of opportunities and choices as the wider community, including strategies to increase the capacity for carers to make choices within their caring roles, transition into and out of caring, and effectively plan for the future.

The main point of any strategy is to enable choice by the carer and by the person being cared for. The greatest tool for choice is money. There are, however, many strategies used to provide the money for necessary services.

I don't know what Mitchell's requirements will be when he is 27 or 52. I have no idea how we will pay for Mitchell's accommodation *if* he is able to leave home and lead at least a semblance of an independent life. Our biggest fear is caring for a 50 year old disabled person when we are 80 ourselves or on our own, with no money, no income, poor health and no hope of any end to our caring duties except death.

Recommendations:

- a. Federal and State Governments should agree to provide a 50/50 split of funding.
- b. Once a diagnosis has been obtained or a carer situation has been entered into, each situation is assessed and an appropriate level of funding provided on a cumulative, yearly basis which is administered by one government body (i.e. Centrelink or Department of Human Services). Funds are accessed similar to a trust fund where applications are made to the government department with a set of clear guidelines available to the department and to those making the application.
- c. Levels of funding should be tiered based on the *realistic* level of care required. For instance, a child with profound cerebral palsy requires 24 hour care. So, too, does a child with severe autism who is in danger of self harm or harming others however their level of funding may be less as there would not be as much required for equipment. This type of assessment is already in place for entry into the school system and could easily be extended.
- d. Whatever level of funding is decided should be reviewed on a regular (possibly every three years) basis and an appeals process should be in place for dispute resolution.
- e. As previously mentioned, funds should accumulate from year to year as some years are more expensive than others and require higher funding than others. For example, a child with cerebral palsy may have a growth spurt and require a new wheelchair, AFO's, chair, bed, etc. all in one year. If funding does not accumulate, the system will be under great pressure each year from carers scrambling hurriedly to spend money they may not need at the time, but would lose if not spent.
- f. Once a person gets to the point where they can no longer be cared for at home, appropriate and timely accommodation should be made available. There are various models available including nursing home or supported accommodation, however the carer and the person being cared for should be able to choose the level of accommodation required for their circumstances.

This is also a perfect fit for a public/private relationship whereby a philanthropic or entrepreneurial organisation funds a series of supported accommodation facilities with tax incentives. At the moment, these facilities are few and far between, and a coordinated approach to providing wider care is sorely needed.

Once again, thank you for providing us with the opportunity to present our ideas for the future of all carers and those they care for.

Yours sincerely,

Leane