STANDING COMMITTEE
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26 JUN 2008
FAMILY, COMMUNITY, HOUSING & YOUTH

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Submission No. 554
(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
P.O. Box 6021
Parliament House
CANBERRA ACT 2600

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.

I am submitting to the Inquiry because....

I am deeply concerned for full time carers, especially those with disabled children, based on my own and others experiences as full time carers. Their physical, social and emotional health is affected and many are unable to work, creating long term financial disadvantage and isolation, which also affects other family members, and will create more costs for the Government in time.

(more information below)

It can be difficult for others to understand what it means to be a full time carer which is sometimes 'for life'. Carers often have worse health than their contemporaries, which is directly related to their responsibilities. Constant anxiety, broken nights' sleep, the physical demands of caring, higher expenses and low income, isolation, and lack of opportunities to have a 'good job' or develop other skills, all take their toll. Many parents of very disabled children hope their disabled child dies first, as they cannot be sure what will happen them when they are not here to care for them.

It can be very difficult for carers who are ill, or 'just having a bad day', as they still have responsibilities to be met, which is particularly hard for older parents. Due to lack of time and finance, carers are unable to enjoy activities which may help their health – walking groups, aerobics, massages, classes, etc. The little time allowed for 'respite' is usually needed to get shopping done quickly or have a medical appointment.

Most of all, carers tend to be silently grieving, whether they realise it or not – grieving for the people they are caring for, worrying because they cannot devote enough time to siblings, and grieving for lost opportunities. Even when the person needing care is admitted to a community residential unit or nursing care, grief continues, as these situations can have disadvantages too. The siblings of disabled children do not have a 'normal life' either, and miss out on a lot of things themselves, and this can carry with them for life too. It may be a 'character building experience' but it doesn't make for much fun in life either!

The role and contribution of carers in society.

As mentioned previously, the role of a carer is a full time one, with many and varied responsibilities, which take their toll physically, financially and emotionally.

Far from the community 'letting carers off the hook' from other responsibilities, they are expected to continue to support schools, kindergartens, etc. especially as they are 'at home' and 'not working'. Some are able to squeeze in a few hours of work, but usually for only a few hours a week.

In addition to this, many carers take on an active role in developing services for disabled people and giving support to each other. Their experiences should be of value in decision making.

They save the Government millions of dollars. I am pleased to see they are 'being heard' at last, as their experiences should be of benefit in decision making.

(more information below).

Family Carers often have to work for the services they need. My disabled daughter is now 43 years old and I have been involved with disability services in various ways (e.g. forming a Toy Library Lending Group and then a support group which brought together parents and professionals). Later on I was on a Committee of Management developing accommodation services and was involved with auxiliaries and a Parent & Friends Group. This was not unique as other parents were involved too.

Today's carers still need to work for good services – in some cases working for the same things that we needed in the 1970's and 1980's. This takes time, energy and finance. I felt we were 'listened to' in the 1970's and 1980's as there was a special department attending to people with disabilities. I don't feel that parents are 'being listened to' the same now, and that in some cases, there is a 'parents keep out philosophy'! The Privacy Act makes it particularly hard for organizations to work together effectively (e.g. day centres and C.R.U.'s) and makes it difficult for parents to meet each other 'without permission'. It has become very complex and made it harder to work together.

Carers need opportunities to be meet and be heard, and this Inquiry is a good beginning. It raises our hopes considerably!

The barriers to social and economic participation for carers.
The practical measures required to better support carers
Strategies to assist carers to access opportunities and choices.

I have put my comments regarding these three questions together, health and financial matters being my greatest concern for carers, as both have long term effects. If these problems are not handled, there will be greater financial implications in the future for the Government.

The needs of carers is varied, just as the needs of the people they care for is different, so there is no one solution for all. However, one major barrier applies to all - **FINANCE.**

In addition to normal family costs of house, mortgage or high rental costs, transport, etc. there are costs specific to illness or disability - medication (my daughter has an average chemist's bill of $70 to $80 per month, which is much lower than some people), transport (some people requiring larger cars for wheel chairs), costs of attending hospitals, and extra everyday costs – washing, drying, heating, special foods, equipment, house renovating, etc.

The accumulation of fees for paid carers also adds up, for those on very limited incomes.

I know the Carers Allowance contributes towards these costs but with the rising costs of many services, I feel this needs a further increase. I am not a full time carer now, as my daughter lives in a CRU, but I am still feeling the financial effects of having been a carer. Other members of family missed out on school camps, we didn't have any holidays at all, and had a very modest lifestyle, as I was only able to work for a very few hours a week. Carers end up on pensions and without superannuation, or health cover.

The health of carers concerns me. Full time care causes fatigue and stress, and 'everyday complaints' such as migraine, arthritis, etc. are increased. Therapies to assist these problems, and to help bad backs, such as physiotherapy, massage, chiropractic, etc. are quite unaffordable. If carers are to continue with very little respite, they must have assistance to keep well. **Health package -** I would like to suggest a health package on an annual basis for Carers (similar to that introduced recently for people with diabetes) where they can be provided with vouchers to meet particular health needs – and be encouraged to seek medical help themselves, for they sometimes ignore health problems 'because they don't have time, and don't have anyone to care for their family member if they need treatment'. **Work safe practices** should be encouraged, with assistance if needed.

Help in the Home must make a big difference, but sometimes it seems as though a tribe of people are all arriving at the same place, with different transport, which itself could seem stressful in a small house. **Multi-tasking,** with staff trained to handle several issues (as they do in C.R.U.'s) could be beneficial.

It is often worrying for carers that staff (especially if they are changed around a lot) may not understand the person's medical condition or behaviour problems as there are many complex problems. **It is most important that these are discussed with the family** carer who has had longer experience. (e.g. Lennox Gastaut Syndrome, which is a form of uncontrolled epilepsy, takes many forms and can be misunderstood. The person can be blamed for behaviour problems when it is a particular type of seizure).

Carers cannot cope physically and emotionally without good breaks, let alone for ever!- Far more residential respite care is needed than is provided at present, and it needs to be more widespread, so that most of the time isn't spent getting there and back. A couple of hours off to do the shopping or see the doctor, is NOT respite!

Emergency care should be available for serious illnesses. (I had a brain tumour shortly after my daughter moved into a community residential unit and don't know what I would have done had she still lived at home). Perhaps there could be 'family packages' sharing resources?

Employment: Most carers probably wish for a 'good job' but this is impossible until there are affordable structures to enable them to train, and then work. Sometimes the only job they know is 'caring' and this may not be what they all want to do – they may wish for a break! They should be encouraged to look at jobs where their experience is of benefit, to strengthen their application for courses or work, unless they have a definite occupation in mind. (I was a School Parent Officer – very few hours and low pay, but relevant!).

Employers should understand that carers may need time off for emergencies, but in the long run they are likely to be more stable as employees as they are unlikely 'to fly the coop' going overseas or leaving.

Getting carers into the work force will be expensive, but bring a good return, if it means independence and better health. Respite may be needed for carers to do field work, or at particular times such as examinations.

Development of housing models should be started now into all levels of caring. Many people will always need live in assistance and this can be denied no longer, although more independent housing models are good for more able people.

Long Stay Care:
It is cruel to have a parent die, leaving someone in need without any known destination. The world of the person being cared for is very small and the few supports they have of parent, house, and nearby friends can disappear in an instant. It is even worse to put

parents in the position of having to abandon their child in order to gain accommodation for them – these are carers who have done all they can to support their child and would never let them down, and they have saved the Government millions of dollars.

In conclusion, the younger carers need to be able to live a normal productive life, with opportunities to work and have some independence, and the older Carers need urgent attention, especially in regard to long term care.

We must not forget, either, that there are very young carers of school age caring for parents and they need every consideration. Their lives are just beginning and their educational and work opportunities should not be limited, although it is inevitable that their social life is affected from being a Carer. Finance is a big factor for them.

Thank you for your consideration of these matters. I look forward to recommendations your committee make to improve life for carers in Australia.

Yours sincerely,

Iris

23rd June, 2008