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Submission No. 848

(Inq into better support for carers)

Lyn

1 July 2008

Committee Secretary,
Inquiry into Better Support for Careers,
House of Representatives Standing Committee on Family
Community, Housing and Youth,
P>O>Box 6021,
Parliament House
Canberra ACT. 2600

Dear Secretary,

BETTER SUPPORT FOR CARERS

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 Careers.

I am submitting to the inquiry because I have a profoundly disabled daughter who is confined to an electric wheelchair, and I see the plight of many who have no one to speak for them.

I have been widowed for 28 years and have brought up four children on my own, the youngest, Victoria, 28 years of age, was 5 months old when my husband died.

I am absolutely frustrated at what I perceive to be a great lack of empathy and understanding at the decision making process by both Federal and State legislators in matters pertaining to profound disability.

I absolutely believe that the Government must address the issue of major and mild disability and legislate to that effect.

I believe that those persons who are unable to care for themselves and who would be placed in residential care or simply die if left in the home without care, must be identified as having much higher needs than those persons who suffer mild afflictions and can live quite independently, and be part of the wider community and do not require very expensive equipment, transportation, personal care, incontinence aids, home modifications, the list is endless.

I would implore the decision makers to actually spend time with those of us who have seriously affected children. A picture tells a thousand words and I believe would assist with the appropriate funding being available to those most in need.

I am concerned that many self inflicted health issues, such as many HIV, alcohol, drugs etc and many who simply do not wish to work, are lumped into the Disability area, and that those statistics and appropriate funds should be a separate body.

THE ROLE AND CONTRIBUTION OF CARERS IN SOCIETY

1. As a carer, I feel that my role is to ensure a happy and safe environment for my daughter. To ensure that all has been done medically and physically to enhance her well being.

. In our situation we have no family in Victoria. My daughter has wonderful siblings overseas and in NSW, so communication with them is imperative. I have strived to ensure that my daughter has appropriate equipment and access to the community. These issues and funding take years and tears to achieve. Again, God help those with little advocacy.

As my daughter gets older, I like thousand of others before me and still to come, live in absolute fear as to what happens when we are no longer able to give the support to our loved one.

I look at some people who live in residential care and despair. I have lots of ideas for an appropriate long term facility for young adults and continue to have discussions.

A full time carer – and I repeat full time carer, many like myself who do it alone, live a life of isolation. It becomes too difficult to go out – by the time toileting, dressing, padding, heavy lifting, loading into van etc, whilst also getting oneself ready and knowing that when you eventually get to your destination the disabled park will 99% of the time have been taken by a person who does not fit the criteria of the Category One permit.

Government must address the issue of Disability Parking and the flagrant misuse of the issuing of the Category 1 permit. I have never seen a Green Permit, which allows twice the time allocated in a parking area for those who may need a little more time.

I know that this problem is on 'an' agenda being addressed at a national level, but it is a VERY slow process. The Government must seriously look at having identification on permits so that those misusing can be dealt with. I do not think for a minute that anyone realises just how much easier it is so access the community with a wheelchair, if a suitable park is available.

I welcome any of you reading this to spend a weekend with us.

I try and work within the community to address some of the issues of the profoundly disabled but it takes time and energy away from the job of caring. Government must be aware that if a profoundly disabled person is away for a part of the day, often that time is taken by the carer to pursue the needs that are required for that person and others.

It is well documented that Government is saving billions of dollars each year by full time Carers looking after their loved one/s at home.

I believe that full time carers should receive the dignity of a reasonable income without being income and asset tested. 24 hour round the clock work is being undertaken. It is time that the FULL TIME care role is recognized as WORK and FULL TIME Carers have a right to be paid for their work.

Older people can obtain aged pensions etc and sit down and not do a thing. It is very discriminatory, as is the Blind Pension, which if someone, however minor the affliction, but be assessed as legally blind, have a lifetime Pension, free of asset and income testing.

Government should ensure a pension that recognizes the work undertaken by a full time Carer and recognize that without that care, the profoundly disabled would not survive in a home situation, and be placed in residential care. They should not be subject to assets or income testing. What other working people in our society are treated in this way.

2.

THE BARRIERS TO SOCIAL AND ECONOMIC PARTICIPATION FOR CARERS

As a carer, I face the following problems: I am too tired and aching to go out at night, and the lack of appropriate carers at call, or any for that matter, is a problem.

A recent excellent example of trying to be part of the community, myself and daughter: We were asked to be part of a small group to go to the movies at Southland for the opening of Sex and the City. God help me! Our young friend booking found out about access and when confirming that we could access the theatre, was informed we could not go as the one wheelchair space has been taken in the 10 minute period.

This, at a time when there were seats available in the Village Gold Class Theatre.

This was the first time in 10 years of residing in Victoria that my daughter had been asked to go out with a small group of 'normal' people.

After much dialogue with management and an appeal to Minister Bill Shorten, nothing eventuated and we were left behind.

On the day of the showing, the group reported back that no wheelchair person was at that theatre.

On advising the Minister and Village Theatre – absolutely nothing happened. Not even a reply to my advice that the disabled area had not been used. How can we make things better if no one cares and follows up.

I attach copies of correspondence of this example for your interest, and for you to understand a little of the social and economic barriers to Carers and their disabled family trying to participate in the community.

Going to the movies is not life threatening or world war three, but is is 2008 and we still are struggling to be part of the Community.

I am also working to ensure a disabled toilet be provided in another area that my daughter accesses and until that is installed she is unable to participate. Many months to date.

The frustration and sadness of countless similar examples, special transport being available, on time. Difficult entry to shops, restaurants, buildings etc. simply means that we go out less..

3. AS A CARER I NEED HELP WITH

Dignity to have a reasonable income for work carried out.

Appropriate funding to be available when required for equipment, home modifications, transport, incontinence etc.

Appropriate respite. Do not expect loving parents to simply accept any respite facility.

We need to know that if our child has respite it is at a facility that understands the child or adult and their needs, and provide first class care and environment.

One usually has to plan many months in advance for respite. How can we have any sort of normal existence?

When we are tired and we ache, and are up all night, or want to have some sort of normal relationship with other family members – who cares or understands.

Long Term Accommodation needs must be undertaken immediately, not only between Government employees, Health Professionals and service providers, but with caring parents and family who understand what is required to ensure that their loved ones have the dignity of living as close as practically possible to a home environment.

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STRATEGIES TO ASSIST CARERS TO ACCESS OPPORTUNITIES AND CHOICES

Again, I believe that the Government must legislate to ensure that Carers of profoundly disabled persons, must be identified, and more financial and practical help be made available.

To allow Carers the dignity of time out without losing entitlements. Example: Respite. The effort of placing someone in respite can take an enormous amount of time, effort and mental anguish, and usually the Carer is too exhausted to make good use of the time left, or is simply doing other things to ensure that their loved ones needs are being addressed. It simply does not stop if one is a full time Carer.

Don't make us all so accountable for every part of our everyday lives. We are on your records and are easily identified.

For policy makers to appreciate the work of the full time Carer and the ongoing hurdles with inclusion and realize that it is all part of the difficulty in allowing Carers opportunities and choices.

Leann Fairbairn
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