Submission No. 1301

(Better Support for Carers)

ADC 5/3/09

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To 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 am a professional Counsellor who has worked with Carers of people with disabilities for 30 years.

I have spoken with Lynne who is the mother and sole carer for her 2 adult sons and whom I have had the pleasure of being associated over a period of 22 years.

Lynne has also made a submission but I have felt strongly the need to offer my reinforcement to this committee of the issues that I have seen emerge not only in this family but also in the majority of other families providing this type of care.

I have Lynne's permission to discuss some of her history.

Parents and Carers play a crucial role in the care that they provide to their loved ones.

The issues that are foremost and that surface continually are :

Marriage breakdown

Sibling

PHONE : 02 61 66 1196 FAX: 02 61 62 0045 EMAIL:nerrylwheatleycounselling@live.com.au Major health problems Physical and emotional such as heart attack, stroke, muscular and tissue damage, depression, suicide etc.

Social problems are lack of support and therefore social isolation, Guilt regarding other siblings and anger from those siblings.

The long term effect on carers such as Lynne are the inability to structure her life so that she can work when her family are raised, the physical deterioration caused by 24 hr care.

This care does not simply entail transporting to and from everywhere but also often personal care, feeding, toileting etc; as well as a constant battle to maintain funding for very minimal programs and regular vocational programs.

It is important to note that there is often no end in sight for carers who have no idea about future accommodation for their loved one should the carer become ill or die.

The fact that most families can work and plan their future without children being their primary care objective causes incredible stress on families where there is no end in sight and they are made to feel that they are not important in the scheme of things and that they should simply carry on.

One of Lynne's sons is now living in supported accommodation after many years of uncertainty and only after he became unmanageable with physical aggressive outbursts.

Lynne's other son is not aggressive but is very physically draining to Lynne who must do everything for him.

He is not seen as a priority and has been overlooked when allocation has been made to other clients.

Lynne has expressed a need to do some payed work but she has also said that as she approaches 50 years this time will be limited and she does not have any sense of control over planning her future.

This is not an uncommon feeling expressed by carers.

They have no sense of control over their loved one's or their own future.

PHONE : 02 61 66 1196 FAX: 02 61 62 0045 EMAIL:nerrylwheatleycounselling@live.com.au Lynne has lost her marriage, she suffers from chronic depression, she continuously has to be aware of time and must lock her home so that her son can not abscond.

Lynne is a very responsible women who certainly has my admiration however admiration will not change the fact that Lynne is still caring for a severely disabled adult son, that she is ageing and her health is deteriorating, that she grieves for the relationship with her 18 year old daughter that other mothers have with their normal adolescents before they leave home and change direction.

I realise that it is not possible to turn back the clock.

We must however look to the future and put realistic support systems and funding in place and listen to the people that are saving this country, this government and our community millions of dollars every day.

Strategies for a better future:

More funding for trained support.

More ongoing funding for group supported accommodation for each category of disability.

More in home support such as respite.

Place a child with a disability on a register for projected supports as soon as the disability is known and update the data base constantly Financial incentives that are realistic and sustainable not insulting and demeaning.

Talk always to the people who know. THE CARERS.

Carers are increasing in number and are one of our most valuable resources.

It is important that you not only listen and pay lip service to this issue but that you act honestly, transparently and with integrity.

Thank you for taking my views into consideration. I look forward to reviewing the outcome of the committee's hearings.

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