

3 July 2008

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

Dear Sir/Madam

Re Inquiry into Better Support for Carers

As the mother and carer of a 28 year old daughter with Down syndrome I wish to submit the following perspectives for the Committee's consideration.

By way of background, I advise that I have been active in many capacities in disability related organizations, including as founding President of the ACT Down Syndrome Association (1987) and, more recently, as an initiator of the recently formed Down Syndrome Australia network. Also, I am a community representative on the board of management of ACT BLITS (ACT Business Leaders – Innovative Thoughts and Solutions) www.blits.org.au. I became my daughter's sole supporting parent when she turned 18. Consequently I consider that I have considerable experience to draw on in expressing the views I have outlined below.

- ***The role and contribution of carers in society and how this should be recognized.***

Overview:

Australian society generally has largely ignored the role and contribution of carers. If discussed at all, carers are referred to as 'wonderful' or 'kind'. People commonly say 'I don't know how you do it.' Others tell you 'I could never do what you do.' But what people do not recognize is that the role of a carer is not generally a lifestyle or career decision; rather, it is thrust upon one by dint of circumstances. Carers take on the role principally because they are humane, caring, responsible and loving. But, despite these wonderful attributes, there are times when carers cannot cope and suffer mental and physical impacts. This should not be allowed to continue to happen in an economically secure country such as Australia.

Because people often do not know how to assist, or feel inadequate, carers can become invisible. Also, carers sometimes do not help themselves in this regard because, not unusually, they put their heads down and accept the role, more or less with a positive outlook, thus becoming the 'experts' who can do what is needed better than anyone else anyway. Over time, carers find that family and friends no longer want to hear about their problems (and who can blame them). It is not difficult to understand that carers often feel

they are looking into a very black tunnel. And it is for these reasons that carers are not often seen to be out there lobbying for themselves, or for the people they care for – or to be even thinking about writing submissions such as this one.

In my own situation, when my daughter was born we (her father and I) made a conscious decision to give her the best opportunities in life we could – as we had decided to do with our older, non-disabled daughter. We had no family living nearby and friends were busy with young children of their own. As parents, we felt it was our responsibility to look after our daughters – and not ask for help. When my daughter with Down syndrome was young there was not much help anyway. Early intervention was undertaken if one had the impetus and energy to participate – and that included the peripheral activities of fundraising for programs and equipment, lobbying for better services including respite, and advocating for the rights of your child and other children with disability.

Services do exist nowadays, but to my observation they are still very limited, inflexible and lacking in imagination and innovation. When one becomes the parent/carer of a newborn child with disability, one needs to be assisted to follow a path which will provide a way forward, with choices to be made relevant to the needs of the child and its family – and the family needs to know that help is there and that, for the good of both the child with disability and the family, they need to use it. All too often, because there is no specific path for families to follow so they can identify a way ahead, they are undermined and demoralized when therapists, service providers and community links break down due to, for example, staff shortages, absences or changes, or organizational restructures, most commonly downsizing (sometimes described as ‘cross skilling’).

In turn, because carers necessarily spend considerable amounts of time ‘doing their homework’ regarding where to go next for services or to problem-solve over and above the day to day physical and mental grind, the stresses and strains on the family as a whole become excessive. This can lead to family breakdown. There is ample research to substantiate this as fact. But why is there seemingly no research into what can be done to forestall family breakdown where there is a member requiring care over and above that required for other family members? Why is it that there appears to exist no research into why it is that fathers – more commonly it would seem – find that they have to leave their family (even becoming depressed, to my observation, and certainly introverted and self-focused) at a point in their lives when they feel they have to move away from a situation in which they can see no light at the end of the tunnel? In my view these are highly important social policy areas worthy of significant research to find ways to enable families to remain cohesive – for their own good and for the benefit of society at large.

In my experience, older carers face many of the above hindrances but have perhaps learned to accommodate them – while still experiencing the frustrations of inadequate support structures. Many elderly parents, it appears, have cared for so long that they cannot envisage any person – let alone a service – being able to care for the person they look after. In fact, often it seems that the role is reversed: the person being cared for takes on some of the caring role of the elderly parent. This is not wrong (and it is often quite touching to observe the care given to the elderly parent), but, unless a path is in place for

the person being cared for, upon the death of the carer the person being cared for is left alone and emotionally bereft.

Carers obviously undertake a wide range of tasks and roles. I am not conversant with the broad spectrum of carers and their roles, but some of the more burdensome examples I know of include:

- parents (often single) caring for children with disabilities – from birth, and with both mild and severe physical and/or intellectual disabilities (and sometimes, as they get older, with depressive or other disabling difficulties such as anger or alcohol abuse);
- caring for elderly parents or other relatives, including in-laws, when the carer too is struggling with infirmity and sometimes disability;
- caring for an elderly mother, the grandmother of the carer's young adult daughter with disability, when the grandmother cannot refrain on any trifling occasion from criticizing and upsetting the grand daughter for her shortcomings. And then, when her daughter (the mother/carer of the grand daughter) tries to calm the situation, the elderly mother turns upon her daughter for allowing the shortcomings due to disability to continue. And
- an elderly grandmother caring for 2 young grand daughters, one of whom has severe disabilities, whilst living with her widowed son (the girls' father) who seemingly has ongoing drug dependency, health and financial problems.

The spectrum of concern for these carers includes (but certainly is not limited to):

- the health and wellbeing of the person they are caring for, including accessing the required medical and other treatments and medication;
- accessing transport and respite care;
- accessing appropriate schooling/work, and 'keeping an eye' on things to ensure 'things don't go wrong' – as they are often wont to do;
- care of clothing and dressing the person, and attention to their personal needs;
- how to advocate and lobby for what the person being cared for needs; and
- organising their financial affairs, and the mountain of paperwork involved in every aspect of their lives.

And, of course, there is the ever present concern about 'what will happen if I'm no longer around.'

My final observation on this term of reference relates to the recognition of carers. In my experience, not only do carers have to physically assist and think, plan and act for the person they are caring for, but also it is common to hear that they are subjected to criticism, animosity, verbal abuse and rejection by family and others. No matter how willing and committed the carer is to their role, anecdotally it seems to be more common than not that the carer has to withstand criticism and suspicion to the point of paranoia from those around them who are in a position to assist but choose not to (and again this choice to 'not assist' is not necessarily wrong). One could suggest that this is caused by a level of guilt which, rightly or wrongly – and probably unconsciously – they are labouring under. So, as well as being unrecognized by society at large for their role as a carer, they are often isolated and ostracized by those nearest and dearest to them.

I have discussed this final observation with staff at Carers Australia and Carers ACT who have advised me that there does not appear to have been any research into this grossly unfair and saddening circumstance. Discussions I have had with my local general practitioner who works extensively with people being cared for at home by a willing family member – and with other carers I know – confirm the veracity of my observation.

I cannot state too highly my view that the greatest – dare I say the only – recognition any carer would seek is the love and support of their family and friends. Given that support, no task is too difficult for any carer.

Recommendations:

- 1. That clear pathways be established for every individual with disabilities – to be reviewed and updated at varying stages of life – with the assistance of relevant support services and involved parties, to enable carers to readily identify and access the assistance and support needed along the way.**
- 2. That research be undertaken into –**
 - (a) the attitudes of family and friends as identified and 'weathered' by carers;**
 - (b) the reasons, as perceived by carers, for these attitudes;**
 - (c) the views of family and friends towards a specific carer;**
 - (d) the views of family and friends regarding how a specific carer might be assisted by them or others; and**
 - (e) ways to change particularly the negative attitudes of family and friends towards carers.**
- 3. That research be undertaken into (building on what existing statistical research there may be into the number of family breakdowns when there is a member of that family with a disability) –**
 - (a) the reasons for family breakdown when there is a member of the family with disability; and**

(b) ways that may assist families with a member who has a disability to recognize and identify difficulties in the marital relationship before the relationship breaks down.

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

As a starting point, in my view one can look at the situation of working mothers to see the complexities involved on a daily basis that have to be dealt with when they return to work – that is, the cost of care, the transport to and fro, the reliance sometimes on family and friends to be a back-up, what happens when there is a medical or other problem, etc. Additionally, the carer of a child with disability has to factor in child specific items of equipment or medication, therapeutic or other specialist appointments, and the extra time involved in dealing with a child's particular needs.

In many cases the role of a carer does not improve as children age and take on more responsibility for themselves. Often an adolescent with disability who wishes to become more independent can be more of a concern when the carer has to 'second guess' regarding the additional vulnerabilities and opportunities for things to go wrong. For instance, they might be able to physically use transport, but if they get on the wrong bus and end up who knows where what can be done to solve the problem?

I have an interminable list of incidents that occurred and needed my immediate attention whilst I was in the work force, including phone calls to say my daughter was threatening to jump off a second floor school balcony due to an upset and, on another occasion, that she was found wandering in a none too salubrious area due to having caught the wrong bus and not knowing how to get out of it. The worry, stress, upset and sheer exhaustion I experienced on a regular basis often left me feeling that my work – though I enjoyed the very challenging job I had – was not worth it. And that is not to mention the military-style planning and organization involved!

The key, as I see it, to enabling carers to find and retain employment rests with flexibility – largely of the workplace. Carers by their very nature are responsible, motivated and conscientious; I contend that these attributes make them very worthwhile and valuable employees. But the person they are caring for is of necessity an enormous distraction. And the carer, too, has to be confident that the welfare of the family as a whole will not be impacted upon.

Recommendations:

- 4. that, as part of the planning process (recommendation 2 above) for an individual needing care, consideration be given to providing a small support group (perhaps 3 people) who are trained to become familiar with the cared for person and the carer so that, when required (even before and after**

school/work), they can step in and provide support on a paid 'on call' as well as rostered basis.

5. that programs be devised to attract carers to enter or re-enter the work force that will include (as well as job matching and specific job training) the ability for carers to identify individually what supports they will need, and that carers be paid an incentive to undertake such programs.
6. that awareness programs and an intensive media campaign be devised to encourage employers to recognize the benefits of flexibility for their workplaces, particularly as related to the employment of people with caring responsibilities.
7. that a job structure/feasibility agency structure be established to assist employers overcome the implications for them of a flexible workplace and to assist employees to meet their responsibilities to both their employer, the person they care for and their broader family.

- *The practical measures required to better support carers, including key priorities for action.*

Australian governments have a long history of giving 'lip service' to the needs of people with disability and their carers. Governments have been quick to adopt the latest philosophical approaches to 'assisting' people with disabilities, particularly when – whilst giving assurances that the appropriate resourcing will be in place – there have been overall cost savings in the pipeline. I instance the moves away from sheltered workshops and institutional or group housing. Governments latterly are moving towards encouraging the corporate sector to take on a larger role, both financially and actively through staff involvement. None of these approaches are wrong, but very little attention is given to assessing whether there are effective outcomes being produced as a result of any changes.

Due to Australia's lack of support for people needing care – and thus carers – there need to be substantial funds made available to the whole sector. But it is not a matter of throwing money at particular services or programs as has happened in the past; it is a matter of starting from scratch – that is, researching what does and does not work for people needing care and their carers. Apart from my recommendations, I am sure many experts in the field of disability studies could name a whole host of vital research topics that should be investigated to create a cohesive and structured approach for the good of not only those needing care and their carers, but also for the Australian community as a whole.

An existing key priority – and one that shall swamp Australian society when one also takes into account the ageing population – is the necessity to enlist, train, inspire and

meaningfully remunerate support workers. In my experience people working as paid carers or support workers include –

- older people who take on a job which is seen as ‘easy’ or without any great responsibility and in which they can work flexible hours;
- students who need to earn some money and find the flexible hours and the ease of picking up work suitable for their requirements; and
- people who are caring and enthusiastic about working with people who need assistance but who soon find that there are no prospects for advancement or progression so leave to find work elsewhere.

These are obviously gross generalizations, but they are indicative of the really critical and urgent need for there to be established a defined career structure in order that people attracted to working with people needing support are trained, retained and rewarded appropriately.

Recommendations:

- 8. That success/failure audits be instigated to assess the viability of existing practices and programs, etc.**
- 9. That a cohesive and structured approach to the disability and carer sectors of the Australian community be formulated.**
- 10. That support worker staffing levels and career structures be addressed urgently.**

- *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.*

In my recommendations above I feel that I have largely addressed the points in this term of reference – that is, by putting reliable support teams in place to assist the carer; by giving the carer a pathway to follow for the person for whom they are caring so that they can have confidence they are moving in the person’s best interests; by providing workplace flexibility so the carer can make decisions in the best interests of the person being cared for and themselves; by the carer having the confidence that they are carrying out their caring role with the support of family and friends; and by having these supports funded at a viable level so the carer can be confident that things will not come unstuck when they least expect it. It is only then, as I know from personal experience, that one

can escape from the mire of day to day caring to consider the future for the carer and for the person being cared for.

It is not good enough for the Australian government to canvass for help; it is the responsibility of the Australian government to lead by example.

Yours sincerely

Evelyn