A.O.C. 7/7/08

Submission No. 512
(Inq into better support for carers)

27 June 2008

House of Representatives Family and Community Committee
Canberra ACT

Dear Sirs/Mesdames

Carers of people with disabilities submission

I make a submission regarding the current inquiry by the House of Representatives Family and Community Committee regarding carers. I set out below my 13 submissions, with accompanying personal information to illustrate the issues.

Background

My 8-year-old son Jack has autism, is intellectually disabled and has attention deficit hyperactivity disorder and I am his primary carer. He is a sweet, happy child who loves music. He cannot speak meaningfully, he has behavioural problems, is not toilet trained, has very limited play skills and he is highly mobile and overactive with effectively no sense of danger. Intellectually he will be like a wild, hyperactive two-year-old for the rest of his life. Medications have had very little effect on him. He requires active adult supervision every minute of the day to ensure he does not harm himself or others or break property.

We live in the eastern suburbs of Sydney. I have three degrees from the University of Sydney including undergraduate law and economics and postgraduate law. For many years I have been unable to do paid work for more than one hour a day due to my son's disability. Both my sons attend primary school five days per week. My income is negligible but my husband works and is very active in caring for our two children.

I am often on the point of total collapse due to exhaustion. Each year my mental, physical and pecuniary resources are substantially diminished by the impossible task of caring for my disabled son. At some time in the future all my resources will be depleted by this task, then I will have to renounce the care of my eldest son to the State. I beg your Committee to work for extreme changes to public supports for people with disability.

Services for people with a Disability

I submit that support services for people with disabilities should be better funded, easier to find and access and more flexible (Submission 1). These issues significantly affect my ability to seek paid employment. As I am almost unable to do anything at the same time as caring for Jack, the absence of a reasonable quantity of respite and the time required to obtain supports for Jack severely restrict my job prospects. If fully publicly funded therapy was available to Jack this would also assist his and my social participation.

Access

My family currently deals with numerous different service providers as follows:

1. Special education school
2. Special education transport service
3. Nappy service
4. Respite services
5. NSW Department of Ageing, Disability and Home Care (DADHC) for occupational therapy and speech therapy consulting
6. Advocacy organisation
7. Parent support group
8. RTA for mobility pass
9. Department of Transport for taxi subsidy
10. Various charities including the Benevolent Society, Sunnyfield, Autism Association
11. Medical specialists

We have in the past also dealt with early intervention services, physiotherapists, private occupational therapists and speech therapists, dieticians and psychologists. Each of these service providers require my time to manage these relationships and regular problems require alterations to services and re-negotiation of management strategies etc.

Due to my education and being a native Sydneysider, I am unusually well-placed to access services for my disabled son. Yet I find the process of obtaining supports for him very difficult and time-consuming. I have tried using case workers or social workers to access services but discontinued these advisers because I found they were less informed about services than I am so they were no help.

Every service for the disabled seems to offer no more than one-fifth the amount of service required, services are often only offered for a short time (then require re-application and waiting) and they are each difficult to locate. They each have individualised, time-consuming forms to complete and often require individualised medical reports that necessitate more cost and more visits to health professionals.

These issues are exacerbated by the gross shortage of public funds for essential disability services including NSW Department of Ageing, Disability and Home Care therapy consulting, accommodation, education and respite. As a result each service has terribly long wait lists, which they are reluctant to admit in discussion with carers. This makes it very difficult to plan to use services.

Each disability service seems too small to be sufficient or efficient.

The time cost in finding and administering so many service providers can outweigh the usefulness of a service. I submit that providers of services for people with disabilities should be aggregated so that users can deal with fewer service providers (Submission 2).

When services have websites, the websites very rarely state all eligibility criteria (eg nature of disability, geographical limits, age, waiting list times etc) and so I must call an enormous number of service providers to find the ones relevant to us. Their eligibility criteria are often impossible to obtain in writing. The process to obtain publicly-funded disability services seems to be, in large measure, 'the squeaky wheel gets the grease'. This is unfair and means the most needy get the least because they are unable to chase down hard-to-obtain services. This also maximises the time costs to service-seekers.

Services would be easier to access if there was a single central database of services containing all relevant information regarding the nature of the service, eligibility criteria, wait times, costs and application forms online. What online databases currently exist are inadequate. Current help lines are similarly insufficient.

Flexibility

Until this month I was on the waiting list for the local respite service (Eastern Respite and Recreation) for over four years and received no service. I called them regularly to try to obtain service but they are hopelessly underfunded. We have just been accepted to their high-support needs group respite, which offers two outings for my son per school term (ie eight per year). Each outing is for 5 hours and costs me $18 for a one-on-one carer for my son as part of a group. This averages 46 minutes of respite per week over a year and provides no flexibility for me regarding days or times.

This level of respite is obviously insufficient for our needs. In addition, it is not efficient having regard to the amount of time I spent calling them and filling out their forms and getting an individualised medical certificate.

This respite service also has some disadvantages for me, for example it may fall on a date on which I cannot use the service; a five hour outing is difficult for my son who is better able to cope with a 2-3 hour outing; and it is in a group with children with unusual behaviour so my son learns problem behaviours from the others in the group etc. These disadvantages may become so great that I will have to refuse even this small service because the costs outweigh the benefits.

I would obtain more benefit for the same cost to this respite service if it was flexible, for example if they allocated me a budget to spend via their service each financial year. A better service would allow me to set the hours and times for a regular fortnightly/monthly wage to a paid carer for a one-on-one outing with Jack for 2-3 hours. This model of service does not need to add an administrative burden to the provider. I submit that this type of flexible respite should be the preferred model.

The same issues of flexibility apply to many services for people with disabilities. Many services are rendered useless by lack of flexibility. I submit that services for people with disabilities should be as flexible as possible, preferably applying a model of allocating a budget for a purpose then negotiating with the person with a disability (and/or their carer where appropriate) for use of the budget in their circumstances (Submission 3).

Respite

The absence of adequate respite is a huge barrier to social and economic participation by carers. I submit that respite is a **key priority** that would be assisted by more funding and more flexibility in the form of respite provided (Submission 4).

For respite, my family sometimes pays a carer take our son on outings for 2-3 hours. Respite in my family is only useful if Jack goes out of our home with a paid carer. In good weather they go to the park or beach. Where can they go when it rains or is dark? The main possibilities are a shopping centre, library, indoor swimming or museum. A shopping centre is dull, library hours are limited and the other possibilities are expensive to pay entry for Jack and the carer.

I submit that the government should arrange for people with a disability and their carers to receive heavily discounted or free entry to **all** federal, state and local controlled public venues including museums, zoos, indoor sports venues such as pools etc (Submission 5). This would be a practical measure to assist carers to increase social participation in their day-to-day role and improve quality of life for people with disability. It would facilitate improved quality respite. This measure also has the advantage of requiring minimal administration by the carer once an identity card system is introduced.

Access to Therapy

My son is not eligible for any fully publicly funded therapy due to his disability. His need for therapy is universally acknowledged and extreme.

We are entitled to a partial refund of a limited number of therapy sessions each year under Medicare if we obtain an Enhanced Primary Care Program from a doctor (and also if we obtain a Mental Health Care Plan). These plans require a large amount of administration, such that doctors are reluctant to provide them and they are a real burden for users. This does not cover the full cost of any therapy session and is limited in number.

A few years ago my son was eligible for publicly funded occupational therapy and speech therapy at the local hospital because he was too young to have been diagnosed with his disabilities. Once his disabilities were diagnosed the hospital advised Jack was no longer eligible for therapy at hospital and hospital staff told me "NSW DADHC is the provider of therapy for people with disabilities in NSW".

NSW DADHC advise me that they provide no therapy, all they provide is limited 'therapy consulting' sessions to parents of the patient. I find these rules so preposterous as to be unbelievable but, as detailed eligibility criteria do not seem to be available in writing to the public, I have no way to verify this.

DADHC also has inordinately long wait times for these 'therapy consulting' sessions. This system ensures that those in greatest need get the least support. It is extremely unfair.

The absence of therapy for people with a disability can have a significant effect on the disabled person's ability to access social settings. This in turn reduces the carer's social participation while caring for a disabled person. In my family this is certainly a difficulty that makes it harder for me to take my son into social settings. Therapists help with teaching self-care and life skills to Jack, creating social stories to assist my son's social interaction, manage his behaviour etc. Having to pay for private therapy and submit to unreasonable administrative burdens for partial funding via Medicare is a significant impediment to the social participation of carers.

I submit that public hospitals should provide therapy to people based on need, including people with disabilities (Submission 6). I submit DADHC should also be funded sufficiently by the federal government to provide actual therapy to disabled patients, not mere half-measures of 'therapy consulting' to carers (Submission 7).

Funding

Cash payments to carers

The funding from both federal and state governments to support people with a disability is grossly insufficient. Federal welfare payments (Carer Allowance and Carer Payment) to carers are terribly low, and the Carer Bonus is at risk of removal. Federal welfare funding to carers should be materially increased to reduce the human tragedy that exists for disabled people and their carers in our rich country.

People with disabilities face hidden extra costs in every facet of life as a result of their disability, for example disability service fees, expensive dietary requirements, specialised equipment, specialised clothing. This is not reflected in payments to carers.

It would also be more efficient to give carers more cash to allow them to purchase services. This would allow more flexibility in the service to better meet our needs and some services can be purchased cheaper by an individual without administrative costs for example respite. I submit that federal welfare payments to carers should be significantly increased (Submission 8).

Funding for services for disabled people

The absence of public services for people with disabilities mean carers must use federal government welfare for basic essentials for ourselves and our disabled dependants. My son requires expensive therapy, specialised equipment and home modifications that are impossible to pay for using carer welfare payments.

I submit that funding for services for disabled people has been shamefully neglected for decades and needs permanent, enormous increases (Submission 9).

Medical expenses tax offset

The income tax offset for medical expenses covers the cost of paying a carer for a person who is blind or permanently confined to bed or a wheelchair. Why (other than obviously to save money) is the cost of a carer only eligible in relation to those limited disabilities? Aside from being an unfair distinction, a person with disabilities such as my son's needs much more care than a person who is blind. So those in greater need get less government support under these current rules.

I submit that the items qualifying for the medical expenses tax offset should be broadened as a **key priority** to include care for those based on a fair test of need (eg all disabled people whose condition requires a high level of support) (Submission 10). This would recoup to family carers 20% of the cost of paid carers to give us a break from an impossible job. It supports flexible respite and would significantly improve carers' opportunities for social and employment participation.

National Disability Identification

State-based identification cards for carers are not available in all states and can cause difficulty when travelling. A national approach may be preferable.

A preferred strategy is to create an identification system for the person with a disability, particularly if they have a permanent need for care. My 8-year-old son has no identification regarding his severe disability and people glancing at him have no idea of the severity of his disability nor his need for a permanent carer. This causes some embarrassment and difficulty in obtaining disability discounts for him on entry fees to venues. If he had a disability ID card which identified his need for a permanent carer, this would also address the possibility of him being with a different carer on different occasions.

Disability identification cards would be the first step in obtaining free entry to large, indoor venues for a person with a disability and their carer. However, care workers change jobs frequently and different members of my family act as my son's carer at different times. I submit that the federal government should issue an identity card for each person with a significant disability identifying their need for care (Submission 11). This should be transferable between carers, that is, available to any carer with the identified person with a disability. This measure would increase social participation by carers while caring and support respite.

Education

Public funds for supports in schools for people with disabilities are grossly insufficient.

My son requires full-time one-on-one carer support at school. This has been determined by the two different schools he has attended. He cannot sit down for more than 15 minutes at best due to his extreme hyperactivity and short attention span. He constantly causes problems for himself and others when indoors and required to keep still.

Public funds do not pay for a full-time aide at school, even for a child with Jack's extreme needs. At his previous mainstream school, partial public funding was available for an aide and the balance ($300 per week) was paid by my family. Nonetheless, he was asked to leave his previous school as they were unable to cope with his disabilities.

Jack now attends a class for children with autism run by Autism Spectrum Australia (Aspect). Aspect is a fantastic charity that undertakes fundraising in order to pay for the aide Jack needs. Funds at Jack's school are so insufficient that the parents of children at his school spend an enormous amount of time fundraising, in addition to looking after their disabled children.

I submit the federal government should increase funding for education of people with disability. Funds should be provided based on need to ensure every child receives at least a minimally adequate level of education, including necessary supports (Submission 12). This would be just and would remove a significant fundraising time burden from carers. Carers would be more able to apply for paid work if they were freed of the burdens of fundraising for their family's fundamental requirements such as access to education.

Recognising Carers

I submit the role and contribution of carers in society should be recognised by the provision of adequate funds directly to carers and to services supporting the person in their care (Submission 13). If my caring role was made easier in this way, I would feel sufficiently recognised. Funding shortages for people with disabilities and their carers give rise to more acute needs than can be addressed by a street parade or other public relations diversions. I urge the Government to direct every cent it can to disability services and not waste any time or money on stunts to recognise carers.