



Submission No. 615
(Inq into better support for carers)

A.O.C. 8/7/08

29 June 2008

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

Dear Secretary

I wish to make a submission to the House of Representatives Standing Committee on Family, Housing and Youth's Inquiry into Better Support for Carers.

My partner and I care for our 14 year old son who has multiple complex disabilities and we are financially struggling because we are required to take extra leave without pay from our jobs to cover the 12 weeks a year of school holidays because there is no care for our son now he has turned 13.

Our son has been attending mainstream vacation care with an extra support worker under the government funded scheme *Special Needs Support Scheme* (SNSS) since he was 5. We have been told by all the services we have utilized over the years that he is no longer eligible to attend once he turned 13 years of age. The services are saying that the funding they receive is not enough to cover the actual cost of an extra worker and that it is no longer an appropriate service because of his age even though the SNSS funding is there for the child until they are 18. We spent months on the telephone trying to figure out appropriate alternatives but could only come up with one small service that can only offer 1 day per week as the waiting list is so long and there are many other families out there in the same position as ourselves.

This has put undue financial strain and pressure on our family as we have to take leave without pay to cover these periods and consequently never get to have a holiday together as a family.

There are services that can provide vacation care for children/youth with a disability but are limited by the funding they receive. I recently learnt through my investigations that FaSCHIA has money available to provide after school and vacation care services to children/youth that have a disability and was totally dismayed to learn that none of the services or government departments that I

have been in contact with was aware of the funding. This included the local government department ACT disabilities and all of the major community services throughout Canberra. A possible solution to this could be when new funding initiatives become available notification could be sent to existing services, community services branches and health departments throughout the relevant state or territory.

The thing that stresses us most about being a carer is there are services out there particularly for carers and respite services but there are no services for the person with a disability to learn and develop important everyday skills such as life skills, social skills and independence. These are complex issues that a lot of people with intellectual disabilities struggle with every day. The potential difference this could make to an individual's quality of life is enormous not to mention the possible cost saving to the Government in the long term and reduction in stress levels to carers. There are already specific programs written that could easily be adapted to suit individual needs in many areas of social and life skills but no one agency or funding that could oversee and provide this much needed resource.

Another way I think the Government could better support carers is by providing a list of services and professionals that are available in each jurisdiction throughout Australia. There is an incredible maze of carers services, recreational, respite, post school options, advocacy, specialists, specialist medical experts etc that are very difficult to navigate. Basically the only way you find out about services your family member maybe eligible for is through word of mouth which is extremely frustrating and distressing especially when you learn of a service that may have benefited the person you care for years to late to make any difference. In some states there is a booklet that is distributed to carers when you make contact with a respite service that give details of most of the services mentioned above. In one State a booklet has been compiled by an individual but is not widely distributed. Perhaps a way of addressing this issue could be the use of a Commonwealth Government Agency such as Centrelink to develop and distribute a booklet appropriate to each State and Territory. This could then be sent out to all people receiving carers payment or carers allowance as well as to services to help carers navigate the multitude of services and access appropriate and relevant programs.

Thank you for taking our views into consideration as part of the Committee Inquiry. I look forward to reviewing any recommendations you make to improve life for Carers in Australia.

Yours sincerely

Carey and John