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Jill

Committee Secretary
Inquiry into Better Support for Carers
House of Representatives Standing Committee on Family,
Community, Housing and Youth
PO Box 6021
Parliament House
CANBERRA ACT 2600

Dear Secretary

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 Carers.

As a Carer, I feel that my role is to care for the personal needs of my grandson who has a developmental delay and degenerative physical disorder. I also try to give him the same opportunities to be a part of the family and community as his able bodied cousins. This requires sourcing suitable recreation opportunities, educational resources (eg communication aids), special toys and equipment, finding accessible playgrounds and parks and providing him with safe equipment in cars, buses, and in the home.

I face the following problems: Gaining access to supports and services is very complicated and takes a lot of time and energy. My grandson's parents have found the system too difficult to negotiate and very challenging to access. All the services we have accessed have been very caring and of good quality. However the range of services and the persistence required to gain access and stay within the system, whilst coping with coming to terms with a complex diagnosis and dealing with grief has placed enormous pressures on our family. There have been times when my grandson's care and opportunities have been compromised because of these stresses.

I need help with the additional financial commitments for things like equipment, nappies, after school and vacation care, special car seats, strollers, as well as saving for our future needs for wheelchairs, home modifications and a modified vehicle. While there is funding or part funding for all these things (except vehicle), there is still a significant financial burden that we need to plan and save for. Also, because we do not know when we will need these things, or how much we will be assisted with funding, we are under additional pressure. I have met many families who are further along than us, who have had to wait months or years for suitable equipment and modifications. This has put great pressures on these families, and has been detrimental to the health and wellbeing of extended families. This is a constant worry as my grandson's parents have already been adversely affected since the diagnosis.

I think the Government can better help Carers by making specific or percentage payments for essential requirements (eg wheelchairs, bathroom modifications). Also, although we do not currently access respite care outside our family, in the future we will need to. It is really important to our mental and physical wellbeing that we can

feel confident that we will have access to these services when we need them. Although service providers are keen to assure us that we will be able to access respite, the whole system seems to be under so much stress, that unless there is significant commitment to these services from government, that may not be the case. Respite services, and timely home modifications and equipment provision (ie not waiting for 6 months for a wheelchair or bathroom modification) are the main concerns that will ease or impede our ability as a family to cope with the challenges we face. Also, families need access to flexible counseling services so carers can maintain work and family commitments, yet still access allied health services for both their child and themselves.

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

Yours sincerely

Jill