

Mr. Steve Deszpot MLA,  
Chair,  
Legislative Assembly for the Australian Capital Territory,  
Standing Committee on Health, Community and Social Services  
GPO Box 1020  
Canberra City ACT 2601

Dear Mr. Doszpot,

The following is my submission to the inquiry into respite care services in the ACT and the Community Forum on Respite care services in the ACT being held in the Reception Room of the Legislative Assembly on 7 April 2010.

In noting the aims of the forum to hear the views of carers and care recipients I am pleased to provide my own view into both my needs and my primary carer needs for respite. In trying to research and address a pressing need that is becoming more urgent for respite for myself in a timely manor that will enable my primary carer to undergo a medical procedure very soon. What after many hours on the telephone, internet research and just plain questioning of the various local disability support, it has become blatantly obvious that options for respite either on a short or long term basis in the ACT are very scarce or almost non-existent for me to access for my primary carer's pressing need.

As a care recipient, my needs are high and I require care provided on a 7/24 basis as quadriplegic of some 49 years. It is not as though my care can be reduced. There are procedures performed for me by my carer, that if not undertaken on a timely manor over each 24-hour period, they can have life-threatening consequences. This need in my care also identifies in me that my care needs are not only high, but are also very demanding on my primary carer and as such impacts on her health and well being. In the interest of understanding my high support needs and not wanting to over-emphasize my need should the Committee need a boots-and-all explanation into my care I am available to expand on this at anytime.

I note that the Auditor-General's Report of May 2009 into Respite Care Services in the ACT identified a number of shortcomings in those respite services it audited. However, it further identified especially for me, that there are insufficient respite care services for individual's with disabilities, primary carers and families who are outside either those disability support services or respite care services. I contend from the Auditor-General's Report that the majority of respite care targeted those already in disability support services. That in it's self further identifies the lack of respite care services that others outside the disability support service system can easily access respite care to meet their need, either as a care recipient or a care provider.

One of the Audit findings although not actually identified in the report was to do with the non-compliance to the National Disability Service Standards. I am a strong believer that compliance is mandatory to any service meeting standards and this greatly assists in the outcome a service is or was designed to achieve. Furthermore, compliance to a standard alone does not always achieve an outcome in the best interest of clients. Any standard compliance must also be accompanied by or have in place a compliance monitoring process that continues to judge through feedback, review and monitoring of the service that it is achieving in the best interest of client outcomes.

I believe I am very resource-full, a good advocate and well experienced in understanding what disability support services are available in the ACT to best help manage my high support needs. That being the case, together with my carer we have yet to find an acceptable respite option for our ever-emerging need. Whilst only being able to give an outline on my own attempt to access respite care over the last two years to meet what is now becoming a more pressing need for us both.

I contend that there is insufficient respite care services in the ACT that those of us with a high care disability that reside at home and have ongoing 24/7 care support provided by a spouse have little or no access to respite. This I believe is as a result of the lack of purpose funding, the inability to identify unmet need and any future planning by address this necessary service.

The ongoing 24/7 care demand for care giving on an individual's primary carer is a thankless task that impacts on the care giver's standard of living. The demand is such that they are unable to have a life of their own. Nor does it even provide them time to either ask for or lobby for the development of respite services that would benefit their own health or wellbeing even though there is a demand in the wider community that is only increasing as the ACT Community ages.

My age and the recently completed ACAT permanent Assessment by ACT Health provides me with the opportunity to access an Extra Age Care Help (EACH) package. It also provides an opportunity for respite in an aged care (Nursing Home) facility. And while some may say that is a choice I should accept, my past experience with age care support services have not always been positive and have come with risks to my wellbeing. The use of these services in the past, have come with inherent risk to me and a need to be vigilant about how my care is provided. While I am strong about training who looks after me, there are aspects on my care that can only be provided in an age care facility by qualified nursing staff, but this same type of care is provided in my own home by my primary carer.

Because I have an ACAT Assessment and if I were to have aged care services provide respite in my own home there are aspects that care that they can't provide and will require community nursing to undertake. The involvement of community nursing in my in-home respite care introduces time constraints that everyday would mean I would not know when they were due

to attend because of there other demands. An EACH package only offers 10 hours per week and no over-night help and has other aspect of the care package that impact on one's ability to have a reasonable lifestyle.

In closing, I contend that currently Respite Services apart from being extremely important for both care givers and care receivers the choices and opportunities in the ACT to access a respite service are almost non-existent, if your needs are high.

Yours sincerely

Mr. I A Trehwella AM

25 March 2010